

COUPLES COPING WITH PARKINSON'S DISEASE:
IMPLICATIONS FOR THE PATIENT, PARTNER, AND RELATIONSHIP

BY

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DISSERTATION

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ABSTRACT

Parkinson's disease (PD) is a degenerative, progressive neurological disorder that primarily occurs in older adults. Psychosocial research related to persons with PD (PWP) is relatively scarce. In particular, the ways in which the disease impacts, and is experienced by, the couple (i.e., the PWP and his or her spouse or other romantic partner) is a largely underexplored area. Such research is strongly warranted because, if chronic illness occurs in the context of a romantic partnership, it can cause major distress for not only the patient, but also, for his or her partner and their relationship. Furthermore, how a couple copes with these stressors may have important implications for the quality of their relationship as well as each individual's mental and physical health. Therefore, the aims of this project were to (a) describe the ways in which PD affects not only the PWP, but also his or her partner and the relationship, and (b) examine how PWPs and their partners cope with these changes in a relational context via social support. Forty-four individual, in-depth interviews were conducted (with 21 PWPs and 23 partners). Interviews were transcribed and then analyzed using grounded theory techniques. Results clearly demonstrate that PWPs and partners encounter a host of difficulties that extend far beyond the physical manifestations of the disease. In addition, data reveal that PWPs and partners help one another in a number of important ways, but that social support is sometimes accompanied by costs and complications. Findings of this study also illuminate strategies that PWPs and partners consider to be effective in managing these costs and complications of support. Results inform the theoretical development of a normative/rhetorical model of social support for couples coping with PD (which explains why and when certain strategies are likely to be effective in managing costs and complications of support in the PD context). The findings have significant practical implications for PWPs and partners in terms of interventions and medical care.

*To Grandpa in loving memory, and to the rest of my family
and the many, many others affected by Parkinson's disease.*

To Dale Brashers, an inspiring mentor who has left a lasting imprint on me.

And to Scott, my partner in everything, now and forever.

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TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION	1
CHAPTER TWO: LITERATURE REVIEW	5
PD and the Patient, Partner, and Relationship	5
Social Support	30
Research Questions	60
CHAPTER THREE: METHODS	62
Considerations for Data Collection: Interviewing	62
Methodology of the Current Project	71
CHAPTER FOUR: RESULTS	77
Psychosocial Challenges and Relational Issues Experienced by PWPs and Partners	77
Communication of Social Support Within Couples Coping with PD.....	135
Conclusion	167
CHAPTER FIVE: DISCUSSION	168
Psychosocial Challenges Experienced by PWPs	169
Psychosocial Challenges Experienced by Partners	177
Relational Issues	182
Communication of Social Support Within Couples Coping with PD	185
Practical Implications	195
Limitations and Directions for Future Research	198
Conclusion	200
REFERENCES	202
FOOTNOTES	223
TABLES AND FIGURE	224
APPENDIX A: Patient Demographic Questionnaire	231
APPENDIX B: Partner Demographic Questionnaire	233
APPENDIX C: Patient Interview Schedule	235
APPENDIX D: Partner Interview Schedule	239

CHAPTER ONE: INTRODUCTION

There were a whole lot of things we couldn't talk about because they were affected by his condition and he refused to talk about it. I was seriously thinking about leaving because I couldn't stand around and watch. He was not eating, he looked horrible, like he was going to fall over and die and I couldn't, I just couldn't do it. I couldn't stand around and watch that happen, and I didn't seem to be able to find anything to do to change that. (wife of a man with Parkinson's disease describing the initial impact of the illness on their relationship; Habermann, 2000, p. 1412)

Parkinson's disease (PD) is a degenerative, progressive neurological disorder for which the etiology is unknown. The National Institute of Neurological Disorders and Stroke (NINDS, 2006a) reported that at least 500,000 Americans have PD, with a higher incidence rate in men than women. The disease occurs worldwide, affects all ethnic/racial groups, and has no cure. The average age of diagnosis is 60 years old, although approximately 5-10 percent of persons with PD (PWPs) are diagnosed prior to 50 years old. Experts estimate the national annual cost to be more than \$6 billion. Due to the fact that PD primarily occurs in older adults, this financial burden to the nation will likely multiply as the elderly population in the U.S. continues to increase. PD is an area clearly deserving of further research not only because of these substantial U.S. public health and financial concerns, but also the detrimental effects it has on those individuals afflicted with it, as well as their loved ones. PD results in trouble with movement due to tremor, stiffness, slowness, and lack of balance. These symptoms can make activities of daily living, such as dressing or eating, difficult. In addition, PWPs frequently experience communication challenges (e.g., related to slurred speech or an inability to concentrate) as well as depression (NINDS). The partners of PWPs also often suffer detrimental effects as a result of

the strain of caregiving (E. Miller, Berrios, & Politynska, 1996) or from the pain of watching their loved one suffer (Habermann, 2000). The progressive nature of the disease may lead members of this population to feel hopeless because of the knowledge that deterioration is inevitable (Dakof & Mendelsohn, 1986).

The Department of Health and Human Services at the National Institutes of Health noted, “researchers are increasingly recognizing the importance of treating the many non-motor and other complications of PD” (NINDS, 2006b, p. 20). Despite this acknowledgment regarding the significance of examining psychosocial issues associated with PD, the ways in which the disease impacts, and is experienced by, the couple (i.e., the patient and his or her partner) remains a largely underexplored area (Hodgson, Garcia, & Tyndall, 2004). Such research is strongly warranted because, as the opening quote of this chapter demonstrates, if chronic illness occurs in the context of a romantic partnership, it can cause major distress for not only the patient, but also, for his or her partner and their relationship (Corbin & Strauss, 1988; R. F. Lyons, Sullivan, Ritvo, & Coyne, 1995). Furthermore, how a couple copes with these stressors may have important implications for the quality of their relationship as well as each individual’s mental and physical health. Therefore, the aims of this project were to (a) describe the ways in which PD affects not only the PWP, but also his or her partner and the relationship, and (b) examine how PWPs and their partners cope with these changes in a relational context.

A form of coping that is particularly relevant to studying illness in a relational context is the exchange of social support. Defined as “what individuals say and do to help one another” (Goldsmith, 2004, p. 13), the communication of social support is often viewed as an expectation of close relationships. Thus, it is not surprising that chronically ill individuals may, at times, attribute positive meanings to actions intended as supportive; *however, social support can have*

multiple meanings, and support that is helpful in some ways may be troubling in others. This assertion is crucial to the normative/rhetorical¹ approach to social support that drives the current project. In explicating this normative/rhetorical perspective, Goldsmith (2004) drew on an assumption established by prior communication scholarship: During any communicative interaction, participants aim to accomplish multiple purposes. That is, any time communication occurs, people are not only engaging in a task, but also attending to goals related to protecting their own and others' desired identities and maintaining or creating a relationship with others in the interaction (Clark & Delia, 1979; O'Keefe, 1988; O'Keefe & Shepherd, 1987). Balancing these objectives can be challenging (Goldsmith, 1992, 2004; Goldsmith & Fitch, 1997). For example, a man with PD whose motor capabilities are diminishing may view his wife's constant assistance with daily tasks like getting dressed, eating, and bathing as largely helpful gestures denoting relational stability. At the same time, he may also feel helpless and distressed by the identity implications of receiving this aid—perhaps worrying that his wife has begun to view him as frail and dependent.

Goldsmith (2004) refers to social challenges like these, which arise as a result of the difficulty of balancing multiple goals (e.g., the task goal of receiving assistance and the identity goal of maintaining independence), as *dilemmas*.² Because dilemmas may impact the outcomes of social support, it is important for researchers to construct normative/rhetorical models of support. Normative/rhetorical approaches explain *why* support attempts are effective or not in managing these dilemmas by examining how well specific aspects of the interaction (e.g., message features, delivery, source, relational context) align with the multiple purposes of the participants (Goldsmith, 2001, 2004; Goldsmith & Fitch, 1997).

Developing a more thorough understanding of the stressors that couples with PD face yields valuable information about this population, about whom social support research is sorely lacking (Schreurs, DeRidder, & Bensing, 2000). Delineating a normative/rhetorical model of support elucidates why certain support strategies are perceived by PWPs and partners as more or less effective in coping with the challenges of PD. This knowledge, in turn, can inform interventions and approaches to health care for couples with this disease. In addition to these significant practical implications, the current project offers theoretical importance as well: Exploring the communication of social support in specific contexts contributes to theory building by allowing for an analysis of commonalities and differences across populations (Goldsmith, 2004).

In the second chapter, I present literature on extant research on (a) psychosocial effects of PD on the patient, partner, and their relationship, and (b) social support. The chapter also highlights gaps in the literature and concludes with the project's research questions. In the third chapter, I describe the study's methodology and, in the fourth chapter, I present the results. Finally, the fifth chapter includes a review and discussion of conclusions, theoretical and practical implications, and limitations and directions for future research.

CHAPTER TWO: LITERATURE REVIEW

Two major areas of work are relevant to this review of literature. First, relating to the study's aim to describe how PWPs, their partners, and the patient/partner relationship are affected by the disease, is the body of research on psychosocial issues in PD. Second, in line with the study's additional aim of exploring how PWPs and their partners cope with these disease-related changes in a relational context, is the mass of literature on social support. Thus, the review of literature that follows is divided into two main sections: (a) research on the psychosocial effects of PD on the patient, partner, and their relationship, and (b) theoretical perspectives on social support, including a justification for the study's normative/rhetorical approach to studying support in this population. At the end of the chapter, research questions are presented.

PD and the Patient, Partner, and Relationship

In this section, I synthesize the research to date on how PD affects the PWP, his or her partner, and their relationship, with an emphasis on matters related to communication. Although I focus on the context of PD, in which such psychosocial research is relatively scarce (Brod, Mendelsohn, & Roberts, 1998), I also adumbrate the chronic illness literature more broadly at times by including studies from other illness populations. I begin with a discussion of several issues relevant to the experience of a patient living with a chronic illness. Specifically, I examine how chronic illness, in general, and PD, in particular, can (a) affect an individual's communication abilities, (b) challenge one's identity, and (c) induce uncertainty. Next, I outline research exploring the experience of the patient's partner, focusing on findings regarding spousal/partner caregiving. Then, I review how chronic illness can affect the patient/partner relationship. The section concludes with a summary of gaps in the literature. In short, this section

presents an overview of the extant literature regarding the psychosocial issues of living with PD (drawing on other illness contexts as well), while also highlighting the need for further research in this area.

Effects of Chronic Illness on the Patient

Chronic illness is a major life disruption (Bury, 1982; Corbin & Strauss, 1987) that may affect the patient in a variety of physical, mental, and social ways. In the case of PD, the patient is likely to experience physical symptoms of tremor; slowness of movement (i.e., bradykinesia); stiffness or rigidity of the arms, legs, or trunk; and trouble with balance. These symptoms often make everyday activities such as getting dressed, walking, and eating difficult. PWDs also may suffer memory and concentration problems as well as depression (NINDS, 2006a). Estimates of the prevalence of depression among PD patients vary; however, a review of studies on PD and depression indicates that nearly one-third of PWDs experience depression at some point (Larsen & Dashtipour, 2008). The mechanism behind depression in PD is unknown: It is unclear whether it is a neurobiological function of the disease. Certainly, another possible explanation is that depression is, at least in part, a reaction to the stress of living with PD (Erickson & Muramatsu, 2004) or the knowledge that future deterioration is inevitable (Dakof & Mendelsohn, 1986). In addition to the aforementioned physical symptoms, these stressors of PD may include a decline in communication abilities (sometimes leading to negative social evaluations), identity challenges, and uncertainty. These psychosocial issues, and the role they play in the illness experiences of patients with PD and other chronic conditions, are discussed in the following subsections.

Impairment of communication abilities. Chronic illness can affect communication in many ways. For example, an individual may wonder whether or not to disclose his or her illness

status to others (Charmaz, 1991). Only certain illnesses, however, actually hinder a patient's *ability* to communicate by interfering with his or her physical and cognitive capacity for verbal and nonverbal expressiveness. This impairment can making coping with an illness even more difficult than when communication abilities are not affected; "the disruption of chronic illness can be further exacerbated when the condition involves a communication disability" (Bute, Donovan-Kicken, & Martins, 2007, p. 235-236). For instance, having a communication-debilitating illness or injury (e.g., stroke, Alzheimer's disease, Huntington's disease) can dramatically impact psychosocial issues such as self-presentation (S. C. Martin, 2010) as well as the way close relationships are maintained (Bute et al.).

A number of researchers have noted a decline in communication abilities as a common occurrence in PWPs. These difficulties often affect individuals even at the early or middle stages of the disease and are not limited to patients with dementia. (In fact, the authors of nearly all of the studies reviewed within this section explicitly stated that nondementia was an inclusion criterion for PWPs to participate in their research.) In some studies, PWPs reported or exhibited impairment in comprehending language. For example, E. Berg, Björnram, Hartelius, Laakso, and Johnels (2003) found that, compared to a non-PD control group matched for variables such as age and education, PWPs scored significantly worse in language comprehension tests (e.g., making inferences from a scenario, counting the number of words in a sentence). This deterioration in comprehension abilities is likely related to concentration problems, which some PWPs have reported experiencing (N. Miller, Noble, Jones, & Burn, 2006). Additionally, individuals with PD may struggle with language production. Approximately 50% of PWPs have speech problems including slurred speech, a lack of vocal variety, or low volume (NINDS, 2006a). Compared to healthy control participants, PWPs also tend to correct their own speaking

errors less frequently (McNamara, Obler, Au, Durson, & Albert, 1992) and make fewer informative utterances (with “informative” defined as accurate, novel, and relevant; Murray, 2000). Moreover, PD patients tend to pause more, which is a result of trying to recall or select the appropriate word to say (Illes, Metter, Hanson, & Iritani, 1988). Some research (Bertella et al., 2002; Péran et al., 2003) has shown that people with this disease particularly struggle with generating verbs (versus nouns), a finding that is consistent with Parkinsonian deterioration in the anterior regions of the brain (Bertella et al.).

These difficulties of language production can, at times, interfere with PWP’s abilities to follow norms of social appropriateness during conversation. McNamara and Durso (2003) had PWP’s as well as control subjects engage in conversation with an “examiner” who was a member of the research team. During or after the conversation, the examiner evaluated each participant using a checklist of communication skills, judging whether the person was appropriate or inappropriate on each skill. Compared to healthy control participants, PWP’s were rated as inappropriate on a significantly higher number of skills (20.4% versus 3.8%), including conversational turn-taking and facial expressions. This latter deficiency refers to the inability to be facially expressive and is a frequently cited symptom of the disease (related to a general slowness of muscular movement). It is sometimes referred to as “masking” or the “expressive mask” of PD (Tickle-Degnen & Lyons, 2004).

To further examine social appropriateness and PD, Holtgraves and McNamara (2010) utilized the framework of P. Brown and Levinson’s (1987) politeness theory. According to politeness theory, people typically are motivated to communicate in ways that minimize threats to their own and others’ face (i.e., desired identity in an interaction). Face-threatening acts (FTAs) may be handled in a number of different ways, from the least polite form (bald on-

record, which entails communicating the FTA bluntly) to the most polite strategy (not communicating the FTA at all). The theory dictates that speakers should use the form of politeness that is appropriate to the situation, which depends on the power difference of the speaker relative to the hearer, the social and relational distance between the speaker and hearer, and the rank of the FTA (i.e., how face-threatening it is). Holtgraves and McNamara presented PWPs and a control group of non-PD patients (who had other chronic illnesses not associated with cognitive impairment) with hypothetical scenarios in which they were asked to imagine making a specific request and to write down exactly what they would say. Scenarios were varied in terms of the power dynamic between the participant and his or her imagined listener and how high-ranking the FTA was. Unlike control participants, PWPs did not vary their politeness based on the rank of the FTA. These results suggest that PD impairs politeness, perhaps because it limits an individual's ability to engage in cognitively complex tasks such as matching language to the situation.

These communicative challenges may affect how PWPs are perceived by themselves and others. For example, in a study by Tickle-Degnen and Lyons (2004), health care practitioners (particularly novices) incorrectly attributed expressive masking (i.e., the decreased ability to be facially expressive) to less extraverted personalities when watching videotaped interactions of patients with PD. In another study examining the impressions of others about PWPs, Jaywant and Pell (2010) had people listen to recorded speech samples of PWPs and healthy control participants. The listeners were not informed whether the speakers had PD or not. Compared to the control group, PWPs were “rated as sounding significantly less happy, friendly, interested, and involved” (p. 54). The authors concluded that, unfortunately, these negative impressions are “likely to have far-reaching effects on [PWPs’] social lives and psychological well-being” (p.

54). Other researchers have focused on the self-perceptions of PWPs and the impressions that their caregivers or partners have of them regarding communication abilities. Some studies have demonstrated that both patients and their partners/caregivers acknowledge that the disease has hindered the PWP's communication abilities, although their evaluations of how severe the impact has been may not match up; McNamara and Durso (2003) found that spouses rated patients' ability as more impaired than PWPs rated their own abilities, whereas caregivers in a study by N. Miller, Noble, Jones, Allcock, and Burn (2008) judged the impact to be less considerable than patients did. In a rare qualitative study exploring the perspectives of PWPs regarding how the disease has changed their communication, N. Miller et al. (2006) found that patients' concerns were centered around the reactions of others (e.g., being ignored); conversational difficulties (e.g., having trouble concentrating); and declines in the intelligibility of their speech and the quality of their voice.

There is a need for further research regarding adaptive ways for PWPs and their loved ones to cope with these communicative difficulties (and the psychosocial issues that they induce). Some research suggests that speech therapy and interventions can be beneficial for PWPs. In particular, group settings may be valuable as they allow not only for vocal exercises but also group discussions about topics such as personal challenges (e.g., Manor, Posen, Amir, Dori, & Giladi, 2005). Perhaps these group discussions might also lead participants to share their personal coping mechanisms, which is an important topic with scant research. The only study I found in which the coping strategies utilized by PWPs for managing communicative impairments were presented was the aforementioned qualitative study by N. Miller et al. (2006). Participants reported coping with communication changes via "physical strategies" (e.g., deliberately speaking slowly to enhance clarity); "monitoring and adjustment strategies" (e.g., being

cognizant of whether their conversational partners could hear them); “managing conversations” (e.g., listening more than talking; using alternative methods of communication like email); and “helping others to understand” (e.g., telling others about the disease; p. 237). Because PD often leads to deficits in language comprehension and production—and these difficulties can impact the ways that PWPs are perceived by themselves and others—more research that contributes knowledge regarding ways of coping with these challenges is needed.

Shifts in identity. Another psychosocial issue commonly faced by patients with a chronic illness is managing identity changes. “Identity” can be defined as the “attributes, actions, and appraisals” of a person (Charmaz, 1987, p. 284) that are constructed and managed through social interaction over time (Hewitt, 1993; Howard, 2000). Communication is linked inextricably to identity in that people negotiate and present their own and others’ identity during social interaction through language (Howard; Tracy, 2002). Identity is formed and externalized by communication (Hecht, 1993; Hecht, Warren, Jung, & Krieger, 2005) through processes such as self-presentation and altercasting. Self-presentation refers to the construction and management of one’s own identity through communication (Goffman, 1959; Hewitt; Leary, 1995; K. A. Martin, Leary, & Rejeski, 2000; Tracy), whereas altercasting is the process by which people put others into roles (i.e., enact their perceptions of others’ identities) through communication (Hewitt; Tracy; E. A. Weinstein & Deutschberger, 1963).

Sociological interest in self and identity within illness contexts began over half a century ago with Parsons’s (1951) work on the “sick role” (Charmaz, 1999). Parsons regarded the role of a patient as a temporary one in which the individual is exempt from normal responsibilities (e.g., work, school); however, more recently, social scientists have recognized that this conceptualization is problematic for the chronically ill patient, for whom illness is a continual

part of life rather than a brief exception (Charmaz). Thus, there has since been a growing body of research focused on chronic illness and how it impacts identity. For example, a number of researchers have theorized that having a disease such as cancer (Harwood & Sparks, 2003) or HIV (Rintamaki, 2009) can lead a person to develop a new social identity as a result of being a member of an illness community. In addition, the experiences of having HIV (Brashers et al., 2003) or undergoing organ transplantation (which often is necessitated by an underlying chronic illness; S. C. Martin, Stone, Scott, & Brashers, 2010) may induce identity shifts that serve as sources of uncertainty.

Other scholars have explored the ways in which manifestations of chronic illness may threaten, or result in the loss of, aspects of a person's pre-illness identity. Based on in-depth interviews with individuals with a variety of chronic conditions, Charmaz (1983) described the "loss of self" that occurs in chronic illness as centered around feeling restricted, experiencing social isolation, facing "discrediting definitions of self" (p. 181; also see Goffman, 1963), and feeling like a burden. Sometimes these identity challenges are related to such facets of identity as gender. Maliski, Rivera, Connor, Lopez, and Litwin (2008), for instance, interviewed Latino and African American men who had undergone treatment for prostate cancer and examined their perspectives on how the side effects of treatment (e.g., erectile dysfunction, urinary incontinence) challenged their masculine identity. Participants reported identity threats "related to work, control, strength, sexual performance, and independence" (p. 1613).

The ways in which patients respond to or manage changes in identity have been investigated as well. Corbin and Strauss (1987) discussed a three-step process of identity reconstitution as part of the "work" of chronic illness. These steps entail "the defining and redefining of identity" (e.g., testing one's body to understand new limitations), "a refocusing of

direction” (e.g., substituting prior activities with new ones in light of current capabilities), and “an integration” (e.g., acceptance of the new identity as a result of validation from self and others; p. 272). Identity renegotiation or maintenance also has been studied in specific disease contexts. For example, in the aforementioned study regarding how prostate cancer treatment challenges identity, Maliski et al. (2008) found that Latino and African American men renegotiated their masculine identity by attempting to normalize their experience (e.g., thinking of side effects like erectile dysfunction as a common occurrence that happens to many men); striking a balance between remaining hopeful about the future and facing reality; considering their own and others’ schema of masculine attributes (i.e., examining beliefs about what it means to be a man); and reprioritizing (e.g., placing lower importance on sexual activity). At a general level, some of these findings overlap with those from a recent study of identity and Alzheimer’s disease; MacRae (2010) noted that participants (Alzheimer’s patients) managed their identity through normalizing and reprioritizing, along with other strategies including focusing on the present time rather than the future, comparing themselves to others, evaluating and making sense of their life, and creating new aspects of identity. Studies such as these extend work on the experience of the patient during illness by examining how identity is impacted by, and managed during, chronic illness.

Although little research has focused exclusively on identity in PD, themes related to identity changes are evident in several studies. A number of factors may contribute to such changes, including a loss of independence (Marr, 1991) and psychological issues (e.g., problems related to stress, sex, sleep, depression, and communication; Macht, Schwarz, & Ellgring, 2005). In addition, PD may lead to personality changes (McNamara, Durso, & Harris 2008), which could impact a person’s self-concept. According to Mendelsohn, Dakof, and Skaff (1995), PD

seems to exacerbate personality changes that occur in normal aging. They found that PWPs and their spouses both reported that the PWP had experienced negative personality changes (e.g., had become more absent-minded, awkward, and dependent, and less ambitious and helpful) as a result of the disease. A similar pattern of changes was present in a control group (including community members and their spouses matched in age to PWPs and their spouses); however, the changes were reported at a much larger degree for PWPs.

Another factor that may play a role in identity changes among PWPs is stigma, which “refer[s] to an attribute that is deeply discrediting” (Goffman, 1963, p. 3). Moore and Knowles (2006) conducted a survey of the general population to ascertain public attitudes about PD. They found that nearly half of their sample believed that there was a stigma associated with PD. A study by Nijhof (1995) suggests that some PWPs do in fact feel stigmatized. Approximately half of the PWPs interviewed expressed shame as part of their experience with PD. Shame was a result of breaking rules related to “social competence” (p. 198; e.g., needing help with mealtime tasks such as cutting food), “public exposure” (p. 199; i.e., having others witness signs of the disease), or being “labeled as deviant” (p. 200; i.e., assuming others are ascribing unflattering identities to them). A disturbing implication of PWPs’ experience of shame is that most participants reported responding to it by withdrawing or retreating from social contact.

Finally, a small number of studies has also addressed how PD impacts specific aspects of one’s identity such as femininity. In a case study analysis of a 62 year-old woman with PD, Bramley and Eatough (2005) found that PD had impaired the patient’s ability to “feel like a woman” (p. 229). Furthermore, the participant noted that she felt her body, which she feared made her appear “senile” or like “an old lady” (p. 230), was a mismatch with “who [she is] inside” (p. 229). Similarly, Fleming, Tolson, and Schartau (2004) presented several ways that PD

may affect womanhood. Using a multiple methods approach comprised of individual and group interviews, diaries, and creative writing, they learned that women with PD may experience a myriad of psychosocial issues including the effects of the disease on body image, sexual relations, and their abilities to be “good” mothers/grandmothers. It seems probable that any of these concerns, like the others reviewed herein, might threaten one’s pre-illness identity. In short, although the body of literature regarding PD and identity is relatively small, there is evidence to suggest that the symptoms and consequences of the disease can pose serious challenges to a person’s identity.

Experiences of uncertainty. In addition to impaired communication abilities and identity changes, individuals affected by a chronic illness such as PD are likely to face uncertainty. In fact, a number of scholars have acknowledged that the experience of illness often is marked by uncertainty (Babrow, Kasch, & Ford, 1998; Brashers et al., 2003; Mishel, 1988, 1990). Mishel (1988) developed a theory of uncertainty in illness in which she defined uncertainty as

. . . the inability to determine the meaning of illness-related events. It is the cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues. Uncertainty occurs in a situation in which the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately. (p. 225)

According to the theory, stimuli relating to symptom patterns, familiarity with events, and congruence between expected and actual experiences are precursors to uncertainty. A patient, therefore, is likely to experience uncertainty when facing inconsistent symptom patterns, a lack of familiarity with health care practitioners or procedures, and unexpected illness experiences.

Uncertainty may be more or less salient based on the patient's cognitive capacity (i.e., the ability to process information) and the resources available to assist in interpreting the stimulus.

Although Mishel's (1988) theory was designed for acute illness, she later expanded it to also include the experience of uncertainty in chronic illness. As a result, this second iteration of the theory (Mishel, 1990) is relevant to the unique, long-term context of chronic conditions, during which uncertainty often becomes a constant way of life. In her review of studies on uncertainty in chronic illness contexts, Mishel (1999) reported that forms and causes of uncertainty in chronic illness include "symptom unpredictability, an unknown future, and the possibility of disease recurrence and extension" (p. 288). By applying and expanding on Mishel's (1990) work, researchers have found that uncertainty in HIV (Brashers et al., 2003) and transplantation (S. C. Martin et al., 2010) can be categorized as stemming from sources that are medical (e.g., unclear information about medical procedures), personal (e.g., identity challenges), and social (e.g., unpredictable relational implications).

The experience of uncertainty among PWPs has not been studied extensively. Nonetheless, there is evidence to suggest that uncertainty is present throughout the trajectory of PD. Before diagnosis, the patient may have uncertainty about the etiology of his or her symptoms. Because the initial symptoms of PD are often subtle (NINDS, 2006a), patients may go undiagnosed for months or even years—which can be a period filled with uncertainty. Furthermore, the occurrence of symptoms is often difficult to predict and, due to the progressive nature of the disease, patients may experience uncertainty about how and when the disease will worsen (Dakof & Mendelsohn, 1986). Another major source of uncertainty among chronically ill patients is the changing nature of one's identity (Mishel, 1999). PWPs may wonder how their roles and activities of daily living will change as their condition progresses; for example, they

may be uncertain about if and how the illness will interfere with their careers, relationships, and plans for the future (Pinder, 1990).

Research on the ways in which PWPs manage their uncertainty is also scarce; however, one study provides some insight. Pinder (1990) learned, through interviews with PWPs and general practitioners, that PWPs sometimes seek, avoid, or selectively search for information to manage their uncertainty. In delineating a theory of uncertainty management, Brashers et al. (2000) proposed that people evaluate uncertainty based on its potential for benefit or harm (also see Mishel, 1988, 1990). This appraisal determines whether a person decides to increase, maintain, or reduce his or her uncertainty via management strategies such as information seeking and avoiding. For example, a patient might view having uncertainty about his or her future prognosis as an opportunity to avoid the possibility of learning upsetting news (e.g., that a rapid decline in health is inevitable). In that case, a person is likely to seek to maintain his or her uncertainty by avoiding information. Conversely, a patient may view an uncertain health prognosis as highly anxiety-producing and, thus, seek information to reduce uncertainty. At times, individuals might also seek conflicting information to increase uncertainty about an undesirable outcome (Brashers et al; also see Brashers, 2001; Brashers, Goldsmith, & Hsieh, 2002).

Thus far, I have reviewed research regarding psychosocial issues that chronically ill individuals are likely to face. Far from being a brief interruption from regular routines, chronic illness often becomes a new way of life for patients, and is likely to induce psychological and social challenges in addition to biomedical issues. Specifically, I have examined the ways that PD and other chronic conditions may impact the patient in terms of impairment of communication abilities, changes in identity, and experiences of uncertainty. Because chronic

illness often occurs in the context of a romantic relationship (i.e., marriage or other partnership), I now shift my focus to consider the experience of chronic illness, particularly PD, for the patient's partner.

Effects of Chronic Illness on the Partner

Considering the difficulties faced by patients, it is logical that chronic illness—and in many cases, the strain of caregiving—can significantly influence the lives of family members, especially partners. Although not all partners necessarily think of themselves as “caregivers” (e.g., in one study, some participants resisted the term and described the support they provided as a natural part of marriage; Habermann, 2000), the role of primary support-provider to a chronically ill patient does tend to be filled by his or her partner. Thus, perhaps it is not surprising that the body of literature regarding the experience of chronic illness for the partner is dominated by research on issues related to caregiving. (In some studies, other caregiving family members, such as adult children, are included in the same sample as partners.) Particular attention has been given to the challenges and effects of caregiving, the role of the caregiver, and factors influencing caregiver adjustment.

Caregiving has been linked to a number of detrimental effects for the caregiving partner including depression and poor health (e.g., Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003). These effects may be brought on by challenges related to financial stress; the responsibility of planning and managing the patient's health care; seemingly incompatible needs (e.g., the need to be strong for the patient but also needing to show vulnerability to seek support); and emotions such as guilt, fear, or anger (Farkas, 1980). The partner also may be dealing with his or her own health issues; in elderly couples, it is not unusual for both members of a couple to have health problems and for one partner to wind up neglecting his or her own issues to take care of the other

person (Huston, 1990). In addition, the partner may be stressed by interpersonal difficulties including changes to the couple's relationship (Corbin & Strauss, 1988; Hinrichsen, Hernandez, & Pollack, 1992). In a study of wives of men with multiple sclerosis, DesRosier, Catanzaro, and Piller (1992) found that, although wives turned to their husbands as important sources of support as well as providing care for them, the "constant proximity [in the home] threatened the husband's potential contribution to the woman's well being" (p. 90). Via focus groups, women reported managing this challenge by spending brief periods of time away from their husbands when possible, sometimes in a space they created for themselves in their home or yard.

Other research has examined the tasks of a caregiver and his or her role in the patient's life. K. Miller and Zook (1997) interviewed caregivers (mostly mothers, partners, and siblings) of people living with HIV or AIDS. (They used the term "care partner" to "emphasize the shared nature of most illness situations;" p. 58.) They found that care partners were involved, to varying degrees, in searching for information about the illness, setting up and/or driving the patient to medical appointments, providing support during hospital stays, assisting with home care, helping with medication regimens, and arranging community services for the patient. In another study exploring the caregiving role, Skaff and Pearlin (1992) learned, from their examination of spouses and adult children caring for Alzheimer's patients, that becoming entrenched in caregiving tasks may lead caregivers to lose aspects of their identity, particularly if outside social contact is limited. Thus, although partners often complete a variety of important tasks as caregivers, this role can come at a cost to their identity.

Some scholars also have aimed to explain why certain partners seem to adjust to caregiving better than others. Corbin and Strauss (1988) named many factors that may impact caregiver adjustment, including the severity of the patient's condition and type of illness, where

the patient is in the illness trajectory, how well the patient manages his or her own symptoms (e.g., medication adherence), and the patient and partner's division of the work involved in managing an illness. Also, research suggests that gender plays a role: Men tend to be less psychologically distressed as caregivers than women (Hagedoorn et al., 2001). One explanation for this is that caregiving is typically a more prominent part of a woman's identity than a man's and thus, it is a bigger identity threat to women than men when caregiving does not go smoothly (Hagedoorn, Sanderman, Buunk, & Wobbles, 2002).

Overall, research on the experience of partners of PWPs mirrors the larger body of literature on partners in a variety of chronic illnesses. Again, the focus is almost entirely on caregiving, and tends to explore its challenges and problematic effects as well as how caregiver burden is affected by certain factors (e.g., PD severity). The problems faced by caregivers of PWPs include sleep disturbances, disruption of household tasks and routines (Thommessen et al., 2002), and reduction of social life (O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006; Thommessen et al.). Moreover, the strain of caregiving may result in effects such as physical health problems (Schrag et al.), psychological distress (E. Miller et al., 1996), depression (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; Schrag et al.), fatigue, and less satisfaction with life (Aarsland et al.). Surprisingly, very little research has explored how partners cope with these challenges, though this type of research might be an important step toward recognizing adaptive and maladaptive ways of coping. An exception is a study of spouses of PWPs in middle life, in which partners reported coping with the challenges they faced (the most predominant of which was seeing their spouse struggle) by preserving their own interests, viewing their own difficulties related to their spouse's PD as

“secondary” to what their spouse was going through, and “encouraging their partner to stay active and involved” (Habermann, 2000, p. 1413).

Research has also revealed several factors that are associated with caregiver adjustment in the context of PD. Evidence suggests that caregiver well-being (e.g., physical/mental health, quality of life) is positively related to a number of patient variables such as the patient’s health-related quality of life (Martínez-Martín et al., 2005), mood (Martínez-Martín et al., 2007), and level of cognitive functioning (Thommessen et al., 2002). Conversely, caregiver well-being is negatively related to patient’s disease severity/stage (J. H. Carter et al., 1998; Martínez-Martín et al., 2007), the patient’s depression (Thommessen et al.), and the patient’s mental symptoms (Aarsland et al., 1999). Additionally, consistent with findings in the general chronic illness caregiving literature, Mott, Kenrick, Dixon, and Bird (2005) found that women are more likely to experience psychosocial distress from caring for PWPs than are men. Finally, in a ten-year longitudinal study, K. S. Lyons, Stewart, Archbold, Carter, and Perrin (2004) found that pessimism of a caregiver early in the PD trajectory predicted later negative caregiver health outcomes. These results demonstrate that patient and caregiver adjustment are dependent on a variety of factors and can influence one another.

In contextualizing these findings, it is important to recognize that, as is true for many couples in general (and, particularly, elderly couples; Huston, 1990), the partner of the PWP may also have a chronic illness. For example, in one study of PD caregivers (who were almost all spouses/partners), about one-third of people providing care for PWPs had been diagnosed with a chronic illness such as hypertension, thyroid disorders, or depression (Schrag et al., 2006). Although it seems likely that the existence of health problems within both members of a couple may blur the lines between support provider/recipient (i.e., both members of the dyad might be

giving and receiving support to and from one another), this issue is not often explored in-depth in the caregiving literature.³ In the PD caregiving literature, the partner of the PWP was almost always labeled as a caregiver without examination of the ways in which he or she might also be the recipient of partner support. Even in the absence of both partners being diagnosed with a chronic illness, it seems likely that the “well” partner may at times receive support from the PWP, yet this also has received scant attention in the literature regarding PD partners. Only in one study, a rare qualitative examination of the perspectives of spouses of PWPs in middle life, did I find mention of the fact that many partners preferred not to think of themselves as “caregivers,” perhaps because it implied that they did not also receive support and care from the PWPs. Instead, they reported, via in-depth interviews, that they viewed the support that they provided for their spouse as a natural part of their relationship (Habermann, 2000). Further research is needed on the ways *both* members of a couple may support one another when one or both partners are chronically ill.

Thus, as demonstrated by the preceding discussion, research in this area reveals the importance of considering psychosocial impacts of PD not only on the patient, but also the partner. Despite strong evidence and widespread acknowledgment that caregiving tends to be associated with negative mental and physical health effects (in chronic illness in general, as well as in the PD population specifically), these problems persist. Corbin and Strauss (1988) noted that there are a number of reasons that many spousal caregivers may not be getting the assistance that they need. For example, some caregivers may not feel comfortable discussing their struggles with others. They may feel guilty at the idea of burdening others (e.g., adult children) by asking for help, or they may be ashamed to admit that caring for their partner has become a stressful task. Alternatively, caregivers might simply be unaware of the supportive resources available to

them (e.g., support groups), or there may be obstacles to utilizing these resources (e.g., not being able to leave the patient unattended to go to a support group). With an increasingly large elderly population in the U.S., more and more partners (or other family members) are bound to become informal caregivers, making this an important and consequential area of study. In extreme cases, caregiver stress may lead to elder neglect, or even abuse (Huston, 1990).

Although researchers have begun to devote some attention to the effects of PD on either the PWP or the partner (as caregiver), few studies have explored the overlapping psychosocial issues of both individuals in the dyad—and how these issues impact the couple’s relationship. I turn now to a discussion of chronic illness and the patient/partner relationship. An examination of how chronic illness, in general, influences romantic relationships illuminates areas for future research in the context of PD specifically.

Effects of Chronic Illness on the Patient/Partner Relationship

Chronic illness occurs in a social context; most individuals have a number of strong and weak social ties and, when a person becomes chronically ill, the effects are not limited to just the patient. As discussed in the previous subsection, relational partners are often tremendously affected, for example, by the strain of caregiving. Another way that chronic illness impacts patients and partners is by changes that occur within their relationship.

Chronic illness may invoke many changes in a couple, including the disruption of relational roles and the nature and quality of their relationship (R. F. Lyons et al., 1995). Chronic illness does not always result in a poorer quality relationship with loved ones. For instance, Bute et al. (2007) found that close social network members of people with a communication-debilitating illness or injury reported a range of relational consequences, including positive effects. It does, however, almost inevitably change the couple relationship in significant ways.

For example, many illnesses (as well as their treatments) have negative physical and psychological sexual effects, which may lead to difficulties in a couple's sexual relationship (D'Ardenne, 2004). Another commonly reported effect of chronic illness experienced by couples is the loss of social life. No longer socializing as a couple may lead patients and partners to feel that they have lost their identity as a couple; some elderly spouses of dementia patients reported that others had stopped treating them as a couple (Lewis, 1998). In many younger couples, relational role changes occur because the person with the illness is the primary breadwinner or caregiver within the couple or family. If the manifestations of the illness render it difficult or impossible to continue to perform the tasks associated with these responsibilities, shifting relational roles is necessary (E. Weinstein & Atwood, 1997); therefore, the partner may begin to take on roles that were formerly filled by the chronically ill individual.

Moreover, both the partner and patient are likely to fulfill new roles in order to manage the illness at home. Corbin and Strauss (1988) theorized that couples coping with chronic illness engage in several different types of "work" including *illness-related work* (e.g., symptom management), *biographical work* (i.e., "the work involved in defining and maintaining an identity;" p. 10), and *everyday life work* (e.g., completing household chores, making meals). Although one partner may be more involved in this work than the other (particularly if the chronic illness is severe and symptoms make it difficult for the patient to perform tasks), most dyads dealing with chronic illness perform at least some individual as well as collective work. Thus, couples must navigate challenges such as how to coordinate tasks so that each individual's work aligns with the other's (also see Corbin & Strauss, 1984).

Different relational patterns exist for how couples take on care responsibilities. Butt and Chesla (2007) interviewed women with endometriosis-related chronic pelvic pain and their

partners, and identified five different patterns of relational interaction regarding the illness. These included couples who were “together but alone,” in which each individual had separate views of the illness and how it should be managed, and collaborative work did not occur; “battling endometriosis together,” meaning that the couple collaborated to fight the illness; “conjoined through disability,” referring to cases in which both members of the dyad had a disability or illness, resulting in a shared bond; “totalized by caregiving,” in which the partner cared for the patient completely, often at the expense of his or her own well-being; and “engaged in mutual care,” meaning that the partner provided care for patient, but was not overtaken by it (p. 574-575). Because managing an illness often occurs in a relational context, studies such as this one (in which relational patterns are examined) are valuable.

In addition to the disruption of relational roles (sometimes related to managing care responsibilities), chronic illness can have implications for how a couple communicates. As previously discussed in regard to patient effects, some illness experiences or events (e.g., stroke, PD) can impair an individual’s *ability* to communicate. This, in turn, can affect the patient’s relationships. In an effort to maintain a relationship in the face of a communication-debilitating illness or injury, loved ones may use techniques such as employing communication strategies (e.g. suggesting words if the patient is struggling to speak), managing topics (e.g., sticking to simple topics), or enlisting the help of a third party to facilitate communication (Bute et al., 2007). Apart from effects on a patient’s physical and cognitive ability to communicate, chronic illness often leads to other communication-related issues that may impact close relationships as well. For example, people may have uncertainty about how to talk to a person who is ill; they may wonder whether the patient would prefer to avoid the topic of illness or be asked about it (R. F. Lyons et al., 1995). The validity of this concern is evidenced by research showing that

requests for information can be interpreted in multiple ways (e.g., as caring or intrusive; Bute, 2009).

There are a number of reasons that people may wish to communicate openly about, *or* avoid discussing, their illness (Charmaz, 1991). For instance, a person with HIV may wish to disclose his or her illness status to seek support; alternatively, an individual may opt not to disclose out of fear of rejection (Derlega, Winstead, & Folk-Barron, 2000). (It is also worth noting that, many times, people's communication falls in between complete disclosure and nondisclosure, such as when one someone provides details about one facet of a subject but refuses to discuss other aspects; Goldsmith, Miller, & Caughlin, 2008.) Partners may strategically engage in openness or avoidance as well. In their study of patients and partners who have experienced a cardiac event, Goldsmith, Lindholm, and Bute (2006) found that partners reported sometimes avoiding talking about lifestyle changes because they did not want to sound as though they were nagging the patient. Conversely, not talking might be interpreted as an indication of a lack of caring and, thus, finding a balance between openness and avoidance can be challenging. Nonetheless, evidence suggests that striving for this balance is worthwhile. That is, although topic avoidance has been linked with relational dissatisfaction (e.g., Caughlin & Golish, 2002), complete openness is not *always* desirable either. Afifi, Caughlin, and Afifi (2007) explained,

Disclosure may be generally beneficial, but not entirely so when the reaction is negative or judgmental. Also, withholding information can be functional, like when both people decide to conceal for very good reasons (e.g., to protect the self and their relationships).

(p. 84)

Similarly, Rolland (1994) noted, "Not all thoughts [among couples coping with illness] need to

be communicated. A functional balance is necessary” (p. 330).

This multitude of changes in a couple’s relationship due to chronic illness (e.g., transitioning into new roles, learning to balance care responsibilities, and experiencing shifts in communication) is likely to be accompanied by uncertainty. As previously discussed, uncertainty is a commonly recognized aspect of the trajectory of illness for individuals; however, Goldsmith (2009) suggested that, in the case of serious illness, uncertainty is likely to be a prevalent occurrence at the dyadic level as well. Both patients and partners may experience uncertainty related to factors including the illness itself (e.g., the possibility of recurrence of symptoms), identity issues (e.g., the implications of sexual difficulties on self-image), the relationship (e.g., relational changes due to caregiving), and communication (e.g., questions about how to talk about the future). Members of a couple may engage in dyadic uncertainty management in which uncertainty is managed collaboratively (e.g., both members of a couple might deliberately avoid a topic in order to maintain uncertainty).

In sum, chronic illness may influence several aspects of a couple’s relationship. Relational roles may shift and couples must learn to individually and collaboratively manage the responsibilities associated with chronic illness. Chronic illness also may affect the way a couple communicates, including openness and avoidance of topics. These changes are likely to result in both members of the couple experiencing uncertainty. Little is known, though, about these issues in the context of PD.

Certainly, PD creates stress within a couple’s relationship; it seems inevitable that the significant negative effects that the disease imparts on PWPs and their partners separately also would influence their relationship. Few studies, however, explicitly focus on this relationship. An exception is a study by Hodgson et al. (2004), who interviewed 10 couples in which one

partner had PD, finding that couples reported that the disease had detrimental effects on their relationship, including stress over everyday activities:

Couples struggled over reassigning duties such as driving, household maintenance, caregiving, child care, and financial responsibility. Between the management of the illness and the maintenance of everyday life activities, half of the couples reported feeling overwhelmed as they adapted to PD. (p. 108)

Despite these negative effects, most couples also reported positive consequences such as PD reinforcing or validating their dedication to one another. Similarly, Habermann (2000) found that some spouses of PWPs reported that the disease eventually brought them closer or had some type of positive effect on their relationship. Although it is encouraging that a number of couples do experience some positive effects on their relationship as a result of PD, R. E. Carter and Carter (1994) found that, overall, PD was related to poor marital adjustment. This may be a result of problems with a couple's sexual relationship (R. G. Brown, Jahanshahi, Quinn, & Marsden, 1990) or a loss of shared activities (Habermann). Further research is needed in this area to more fully understand the effects of PD on marital well-being. Finally, although a substantial body of literature has examined how PD affects communication abilities, very little research exists about other types of communication changes (i.e., those *not* linked to motoric/cognitive capabilities).

Rationale for Further Psychosocial Research in the PD Context

This review of the psychosocial issues related to PD has highlighted several relevant areas ripe for future research. First, although some studies have examined the ways that PD can hinder a PWP's communication abilities, there is a need for further research regarding adaptive ways for PWPs and their loved ones to cope with these communicative difficulties (and the psychosocial issues that they induce). Second, evidence suggests that the symptoms and

consequences of the disease can pose serious challenges to a PWP's identity; future research should also explore this in regard to how a partner's identity is affected. Third, uncertainty is widely recognized as a common part of the chronic illness experience (Babrow et al., 1998; Brashers et al., 2003; Mishel, 1990, 1999), yet the experience and management of uncertainty among patients in the PD context has not been extensively studied. Fourth, research in this context most often views partners as "caregivers" without recognizing that caregiver/recipient roles might be fluid at times. That is, the "caregiver" may also receive care and support from the PWP, which points to the importance of studying coping with PD from a relational perspective. Fifth, future research might investigate the partners' perspectives more broadly to encompass other aspects of their experience besides caregiving. For example, some research suggests that a patient's loved ones may experience uncertainty during chronic illness (e.g., Donovan-Kicken & Bute, 2008; Goldsmith, 2009; Stone & Jones, 2009), but uncertainty has not been explored among partners of PWPs or at the dyadic level. This topic is worthy of consideration because uncertainty about relationships has been negatively associated with marital quality (Knobloch, 2008). Finally, research examining the effects of PD on couples is lacking (e.g., in terms of relational roles and openness/avoidance of communication), and this type of work would be a valuable step toward creating interventions for this population.

In conclusion, chronic illness clearly has significant and far-reaching effects on the lives of patients and their loved ones. In the first of two main sections contained within this chapter, I have reviewed research on stressors of PD affecting the PWP, his or her partner, and their relationship. Further psychosocial research in this context is needed, particularly regarding couples' experiences and how they manage changes related to the disease. In the subsequent part

of the chapter, I discuss one of the ways through which individuals and couples may cope with PD: social support.

Social Support

In this section, I review the literature on social support, with a focus on theoretical perspectives. I begin by briefly describing the three approaches that have dominated this literature—social network, psychological, and communicative/interactional approaches. I then discuss several theoretical frameworks, along with the major findings associated with them. I have chosen theoretical models that are especially relevant to a dissertation stemming from the field of communication (i.e., perspectives that began as, or have evolved into, communicative/interactional approaches), including (a) matching models of support, (b) joint coping models, (c) comforting models of support, and (d) a normative/rhetorical approach to communicating social support. Next, I discuss previous research on social support in the context of PD. Finally, I outline an argument for using a normative/rhetorical model framework for the current project. After the conclusion of this section on social support, the chapter ends with a presentation of the project's research questions.

Overview of Approaches to Studying Social Support

In the past several decades, many definitions and operationalizations of social support have emerged (Hupcey, 1998; Sarason & Sarason, 2009; Vangelisti, 2009; Williams, Barclay, & Schmied, 2004). Burleson, Albrecht, Goldsmith, and Sarason (1994) noted that, “Most early definitions referred to an emotional caring dimension” but “increasingly, scholars have come to conceptualize the process of supporting others as an interactional or communicative process occurring between people” (p. xii). The large body of work on this topic comes from disciplines as varied as epidemiology, sociology, psychology, and communication (Burleson & MacGeorge,

2002). This literature can be characterized by three broad types of approaches, each representing a different way of viewing social support—social network, psychological, and communicative/interactional approaches (Burleson et al.).

Social network approaches. Research in the social support field began in the 1970s with social network approaches, which focus on the influence of social ties on health. Researchers in this tradition typically study how the number of ties that a person has (i.e., how many people he or she interacts with regularly) and features of his or her social network affect coping and health (Burleson et al., 1994; Cutrona, 1996). For example, involvement in a wide range of social relationships has been linked to longevity and reduced incidence of depression and physical illness. One explanation for these benefits of social integration stems from Durkheim’s notion that “stable social structure and widely held norms are protective and serve to regulate behavior” (Brissette, Cohen, & Seeman, 2000, p. 54). Critics of this perspective, however, have asserted that objective factors such as the size and structure of a social network are not indicators of the quality or even, necessarily, the availability of support; some ties may not provide support at all whereas others might provide support that is unhelpful or even stress-inducing (Burleson et al.). These critiques prompted a reconceptualization of social support from the viewpoint of the recipient, thus leading to the next wave of research on social support.

Psychological approaches. This second approach, which stems from a psychological perspective, is centered on perceived support (Burleson et al., 1994). Perceived support typically is measured as a person’s perception that support is generally available or would be available if needed, although some measures capture satisfaction with support instead of, or in addition to, its availability (Sarason, Sarason, & Pierce, 1990). Perceived support often has been linked to positive mental and physical health outcomes; however, the mechanism behind this association is

not well-understood (Lakey, McCabe, Fisicaro, & Drew, 1996). That is, although many findings seem to imply that the exchange of social support offers protective health benefits, some studies have shown a lack of congruence between perceived support and actual support behaviors (i.e., enacted support). For example, in a study exploring the exchange of support among members of a couple, Bolger, Zuckerman, and Kessler (2000) found, via a daily diary design, that the support one person described providing was often not reported by the intended recipient. Similarly, some studies indicate that perceptions of support may not be driven by the receipt of support but, instead, by other factors (e.g., personality characteristics; Pierce, Lakey, Sarason, Sarason, & Joseph, 1997). For instance, in three studies examining how support judgments are determined, Lakey et al. found that, across these studies, the most important factor contributing to support perceptions was the interaction between the person perceiving the support and the person providing it. Mechanisms behind this interaction may include the match (or mismatch) between the preferred support styles of the perceiver and provider, as well as the ability of the perceiver and provider to relate to one another.

In this vein, critics of this perspective have noted that, in operationalizing social support as perceptions of support, researchers utilizing a psychological approach are measuring a cognitive belief or schema rather than the enactment of supportive behaviors. In fact, some research suggests that, although the *perception* of support availability has positive effects on a person's well-being, the effects of actually *receiving* support are mixed (Reinhardt, Boerner, & Horowitz, 2006). Burleson et al. (1994) asserted that there is a need for "research providing detailed examinations of the communicative and interactional processes through which social support is solicited and conveyed" (p. xvii). To that end, there has been a move towards a third approach, communicative or interactional perspectives.

Communicative/interactional approaches. Researchers utilizing this third approach conceptualize social support as communication and often study interaction that occurs within close relationships. Burleson et al. (1994) argued, “Social support should be studied as communication because it is ultimately conveyed through messages directed by one individual to another in the context of a relationship that is created and sustained through interaction” (p. xviii). Following this reasoning, Burleson and MacGeorge (2002) named several distinct features of communicative/interactional approaches. First, this type of perspective focuses on communication as the mechanism through which support is exchanged. Rather than measuring perceptions of support or social ties (as the psychological and social network approaches, respectively, do), communicative/interactional approaches typically assess enacted support (i.e., the actions a person has taken, or the words an individual has said, in an attempt to help someone else; Goldsmith, 2004). Although most measures of enacted support require that participants self-report experiences of support—and are thus, in a sense, based on perception—enacted support is different than perceived support because it deals with specific behaviors that have occurred as opposed to general perceptions of support availability (Goldsmith).

Other features that distinguish this perspective from the other approaches are that it assumes a link between quality of communication and outcomes and, unlike the social network and psychological approaches, it recognizes that more support is not always better (Burleson & MacGeorge, 2002). To explain, the benefits of social support (e.g., positive health outcomes; Albrecht & Goldsmith, 2003) often have been accounted for by the buffering hypothesis.⁴ Buffering models of support maintain that social support protects against the negative impact of stressors, thereby diminishing the deleterious effects of stress on health and well-being (Cohen & Wills, 1985); however, the findings of studies examining this hypothesis vary widely, with some

studies reporting that enacted social support actually is associated with *increased* stress (Goldsmith, 2004). Researchers have tried to reconcile these surprising findings about the sometimes negative effects of social support with the intuitive belief that enacted support reduces stress (Goldsmith). One explanation, unique to the communicative/interactional perspective, is that the quality and appropriateness of the support communicated are crucial links between social support and well-being; Albrecht and Goldsmith concluded that “a reason for the mixed, null, and negative findings on the effects of enacted support is that measures of the sheer amount or frequency of support received overlook the quality and appropriateness of the support” (p. 270). That is, studies that focus only on the amount of support ignore the important consideration there are more and less effective ways in which support can be enacted: The manner in which support is communicated (including factors related to the source, context, message, and recipient) may impact the outcomes of the supportive attempt (Burleson, 2009).

In the following subsections, I delve further into the communicative/interactional approach by discussing four theoretical perspectives with varying explanations for the effects of enacted support and how they come about. First, theorists of matching models of support (e.g., Cutrona & Russell, 1990; Cutrona & Suhr, 1994) have argued that support may be more or less effective based on its congruence with the situation. Second, proponents of joint coping models (e.g., Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; C. A. Berg & Upchurch, 2007; Bodenmann, 2005; R. F. Lyons, Mickelson, Sullivan, & Coyne, 1998) have proposed that joint coping (sometimes called communal, dyadic, or collaborative coping) can buffer stress. Third, scholars utilizing comforting models (e.g., Bippus, 2000, 2001; Burleson, 1994, 2003; Jones & Guerrero, 2001) have placed their central focus on features of supportive messages. Finally, in describing her normative/rhetorical framework, Goldsmith (2004) asserted that paying attention

to the multiple goals or purposes of communication can lead to an understanding of more and less effective ways of conveying social support.

Theoretical Perspectives

Matching models of support. Some scholars have theorized that the efficacy of social support depends on the match between the type of support provided and either the support-seeker's goals in disclosing the problem (Horowitz et al., 2001) or the nature of the particular stressor (Cutrona & Russell, 1990; Cutrona & Suhr, 1994). In their proposition of an optimal matching model of social support, Cutrona and Russell hypothesized that support is most likely to alleviate stress when it is congruent with the demands of the situation that the distressed person is facing. They noted that social support is multidimensional and outlined five different types of support, along with four dimensions of stressful situations, from their review of relevant areas of research.

To begin, according to the tenets of the optimal matching model, five dimensions characterize social support. First, *emotional support* involves expressions of comfort, affection, and concern. This type of support may entail empathizing or sympathizing with someone, conveying love or friendship, or checking on someone's welfare. Second, *network support* represents a person feeling like he or she belongs to a social group that is based on shared interests (e.g., a support group). A third dimension of support, *esteem support*, entails offering encouragement or reassurance about a person's capabilities and worth. Fourth, *tangible aid* includes the provision of resources and assistance that facilitate coping. For example, dropping off meals and offering rides to medical appointments are forms of tangible aid that might be useful for a patient recovering from surgery. Lastly, *informational support* refers to giving a

person facts or advice that relate to the stress that he or she is experiencing (Cutrona & Russell, 1990; Cutrona & Suhr, 1994).

Moreover, these five types of support can be classified as either *action-facilitating support*, meaning they are intended to help a person take steps to eliminate the stressor, or *nurturant support*, referring to a focus on consoling the person. According to Cutrona and colleagues, tangible aid and informational support are action-facilitating, whereas emotional and network support are described as nurturant. Esteem support, however, may serve both functions; it might instill self-efficacy (which, in effect, could lead a person to take action towards the elimination of the stressor) as well as provide a consoling reminder of self-worth (Cutrona & Russell, 1990; Cutrona & Suhr, 1994).

These varying dimensions of support are integral to the optimal matching model because it predicts that the outcome of supportive actions depends on how those actions fit with attributes of the stressful situation. In addition to dimensions of support, Cutrona and Russell (1990) described four aspects of stressful situations that might affect which type of support would be the most effective in alleviating stress. First, *desirability* refers to the valence of the event. Although many stressful situations are considered to be negative (e.g., chronic illness), others are regarded as overwhelmingly positive in nature (e.g., getting married). A second attribute, *controllability*, involves whether it is possible for the person to influence the existence of the stressor. For instance, being the victim of a crime is an example of an uncontrollable stressor, whereas choosing to move to a new city is a controllable stressor. Third, *duration of consequences* refers to how long the effects of the stressful situation last. Some stressors (e.g., the death of a loved one) are likely to impact an individual for months or years, whereas other stressful situations (e.g., a high-pressure meeting at work) may affect a person for just hours or days. Finally, a

fourth dimension, *life domain*, is based on which area of one's life is affected by the stressful situation. It includes stressors related to assets (e.g., financial difficulties), relationships (e.g., divorce), achievement (e.g., promotion or demotion at work), and social roles (e.g., retirement; Cutrona & Russell).

Based on these dimensions of support and stressful situations, Cutrona and colleagues made a number of predictions about which type of support would be optimal for varying stressors. For instance, they hypothesized that action-facilitating support (e.g., tangible aid) would be the most effective type of support in the case of controllable events. Conversely, they posited that nurturant support (e.g., emotional support) would be the most beneficial assistance in the context of uncontrollable stressors (Cutrona & Suhr, 1994).

Although matching models such as this one offer face validity, empirical tests have yielded mixed results (Burlinson & MacGeorge, 2002; Goldsmith, 2004). For example, in their study of health behaviors among African American church members, Thrasher, Campbell, and Oates (2004) hypothesized that “instrumental and informational support will be associated with both physical activity and healthy dietary practices, whereas only emotional support will be associated with CRC [colorectal cancer]-screening compliance” (p. 194). These hypotheses were grounded in optimal matching theory's proposition that emotional support is most beneficial in the context of stressors perceived as uncontrollable, coupled with the authors' belief that “individuals perceive greater control over physical activity and diet than over CRC screening” (p. 194-195). Results supported some, but not all, dimensions of these hypotheses in regard to optimal matching theory: Consistent with the authors' predictions, informational and instrumental support were associated with certain dietary practices (i.e., fruit and vegetable consumption), whereas emotional support was associated with CRC-screening compliance. In

contrast to the hypotheses, though, informational and instrumental support were not associated with physical activity or dietary fat intake. Further research is needed to determine the role that the specific disease context may play in these results.

Similarly, earlier research based on optimal matching models also raised questions regarding the validity of this theory. In two studies of married couples in which one spouse was asked to disclose a stressor while his or her partner took the role of support-provider, Cutrona and Suhr (1994) found little evidence to support the optimal matching model. In fact, they found that, contrary to the model, several dimensions of support did not vary in perceived effectiveness based on controllability. These results led them to conclude, “It appears that the optimal matching model was a significant over-simplification of a complex phenomenon” (p. 132).

Some scholars have since provided insight regarding why matching models are not empirically sound. At least five conceptual deficiencies have been identified in the reasoning underlying these models. First, and most problematically, matching models treat all messages of the same type or dimension of support as equally effective and, thus, ignore the fact that messages may differ significantly in quality (Burleson & MacGeorge, 2002; Goldsmith, 2004). In criticizing matching models’ lack of attention to the quality or substance of the support, Goldsmith noted that in such frameworks, “Providing a recovering alcoholic a ride to an AA meeting would not be differentiated from providing a ride to the liquor store” (p. 83). This failure to evaluate the substance of supportive attempts means that each instance of support is counted the same, such that frequency takes precedence over quality. Second, matching models fail to recognize that stressful situations are multifaceted and typically cannot be resolved with merely one dimension of support (Burleson & MacGeorge). To say that there is one “optimal” type of support for each stressor ignores the possibility that, for example, a person who is chronically ill

may benefit optimally from the receipt of both financial assistance with medical bills (tangible support) *and* expressions of concern (emotional support). Third, matching models present a one-dimensional view of communication in which each message serves only a single function (e.g., to provide information); however, in the field of interpersonal communication, it is widely recognized that messages often have multiple purposes (e.g., providing information while also conveying concern; Burleson & MacGeorge; Clark & Delia, 1979). Fourth, matching models assume that support facilitates coping, yet they do not attend to communication processes or features that influence outcomes of social support (e.g., the sensitivity with which the message was worded; Goldsmith, 2004). Finally, the way a stressor is discussed can impact how it is viewed and experienced, but matching models ignore the role that communication can play in shaping or defining a situation (Goldsmith, 2004).

Joint coping as a form of support. In this subsection, I discuss a second type of theoretical approach—joint coping as social support. The majority of research on coping and illness has focused on how an individual appraises and adjusts to stress (e.g., Lazarus & Folkman, 1984); however, when coping occurs collectively, this joint process can be a form of social support (Thoits, 1986). Goldsmith (2004) noted that, in close relationships, the roles of support provider/recipient can become blurred because relational partners often experience shared stressors. Lending support to this idea is a study by Coyne and Smith (1991); they found that, among couples in which one person had experienced a myocardial infarction, partners were just as distressed as patients, making relationship-focused coping (i.e., how patients and partners “deal with *each other*,” p. 410) an important area of study. In fact, some researchers have called for “a reconceptualization of coping and social support as relational phenomena” (Goldsmith, 2004, p. 117).

For example, R. F. Lyons et al. (1998) described *communal coping* as a process in which individuals band together to face a challenge. Communal coping occurs when three elements are present, including (a) a communal coping orientation (e.g., a desire to work together to overcome a given obstacle); (b) communication about the stressor (e.g., discussion about the situation); and (c) cooperative action (e.g., jointly enacting strategies aimed at lessening deleterious effects of the stressor). Communal coping can occur in newly established or long-standing groups. Although communal coping can occur in a dyad, the participants can also include a large group of people (e.g., an entire community). For instance, Lawrence and Schiller Schigelone (2002) investigated communal coping among residents of a retirement community. They found, via interviews with 11 participants, that the stressors related to aging are sometimes viewed as shared problems and noted, “This sense of ‘solidarity in aging,’ that is, the feeling of being ‘in the same boat’ with others facing similar challenges, can pave the way for a culture of communal coping” (p. 700). Members of this community did in fact engage in communal coping behaviors, such as using the “buddy system” (e.g., neighbors checking on one another each morning).

A related concept, *dyadic coping*, focuses solely on the coping efforts of romantic partners (Revenson, Kayser, & Bodenmann, 2005). Other than this difference in focus (i.e., dyadic coping refers to coping among couples, whereas communal coping can occur in a couple or a nonromantic dyad/group), the distinctions between dyadic and communal coping are quite subtle and difficult to decipher. Scholars using these terms, and the less commonly utilized term “collaborative coping,” seem to be referring to the same underlying concept of jointly coping with a stressor viewed as shared; however, they rely on varying descriptions and operationalizations. I have chosen to dedicate more attention within this section to dyadic coping

simply because it seems to be the focus of a larger body of empirical research than communal coping.

Dyadic coping includes processes such as everyday communication, giving and receiving emotional support, and appraising and dealing with stressors jointly (e.g., viewing stressors as “ours” rather than “mine”). Bodenmann (2005) noted, “One cannot examine one partner’s stress appraisals or coping efforts without considering the effects on the other partner and the marriage” (p. 36). This perspective advances the idea that, when faced with a stressor (such as chronic illness), both partners must utilize resources to restore stability to each individual as well as to the relationship.

Some researchers (e.g., Bodenmann, 2005) have noted differences between dyadic coping and other types of social support. First, social support in general can come from a variety of sources (e.g., friends, coworkers), whereas dyadic coping focuses on the exchange between romantic partners. Second, unlike some forms of social support, “dyadic coping is not an altruistic behavior but an engagement of both partners in order to assure the partners’ satisfaction and well-being, which in turn assures one’s own marital satisfaction and well-being” (Bodenmann, p. 39). That is, in addition to having a desire to support their partner, people may engage in dyadic coping to maintain the stability of the relationship and reduce their own stress as well.

Research on dyadic coping can be organized into two different approaches (C. A. Berg & Upchurch, 2007; Bodenmann, Pihet, & Kayser, 2006). The first line of research, coping congruence, assesses the coping techniques (e.g., problem-focused, emotion-focused) used by each individual in the couple, and the extent to which partners’ strategies overlap or diverge. In this approach, each person typically reports on his or her own coping behaviors, and the overlap

between partners' coping methods is identified (C. A. Berg & Upchurch; Bodenmann et al.). The hypothesis behind most studies examining coping congruence is that couples who use congruent strategies will be less distressed than couples using discrepant strategies; however, this reasoning has not generally been supported, with the results of some studies suggesting that relational satisfaction is affected by whether both members of the couple use coping strategies that are effective or ineffective rather than on congruence (C. A. Berg & Upchurch).

In contrast to this first approach in which the individual coping styles of partners are compared for congruence, the second approach "views coping as a genuine dyadic phenomenon" in which both partners are involved (Bodenmann et al., 2006, p. 485). In the second approach (e.g., Coyne & Smith, 1991), a person's perceptions of his or her partner's level of support and involvement are measured more directly, with the assumption that the coping responses of one partner are influenced by the coping techniques of the other. One of the most predominant theories falling under this approach is Bodenmann's (2005) systemic-transactional dyadic coping perspective. According to this theory, the verbal or nonverbal communication of one partner's appraisal of a stressor activates both partners' coping reactions. An assumption of this theory is that dyadic coping must be examined from a systems approach, meaning that a partner's coping strategies and experience of stress cannot be studied without taking into account the role of, and impact on, the system (i.e., the other partner and the relationship).

Another assumption of Bodenmann's (2005) systemic-transactional dyadic coping perspective is that there are both positive and negative (i.e., constructive and destructive) forms of dyadic coping. He named three kinds of positive dyadic coping, including (a) positive supportive coping, (b) common dyadic coping, and (c) delegated dyadic coping. The first positive form, positive supportive coping, is marked by one partner helping the other in his or her

attempts to cope (e.g., helping with routine duties, communicating confidence in the partner's abilities). The second positive form, common dyadic coping, occurs when both partners engage equally in the coping process (e.g., through collective problem-solving). Although the focus in positive supportive coping is to help one partner manage a stressor, in common dyadic coping, partners perceive that they are experiencing and coping with stress together. Finally, the third positive form of dyadic coping is delegated dyadic coping, in which one partner assumes the other's responsibilities in an attempt to help alleviate his or her stress.

Bodenmann (2005) also discussed three negative forms of dyadic coping, including (a) hostile dyadic coping, (b) ambivalent dyadic coping, and (c) superficial dyadic coping. In the first negative form, hostile dyadic coping, the partner provides support in a manner that disparages the other. The second negative form, ambivalent dyadic coping, occurs when one partner provides support while conveying an attitude that he or she does not want to, or should not have to, help the other cope. Finally, the third form of negative dyadic coping is superficial dyadic coping. This form of dyadic coping involves a partner providing insincere support (e.g., asking emotion-based questions but not listening to the partner's responses).

Researchers have explored how these positive and negative forms of dyadic coping (or similar forms classified differently outside of the systemic-transactional perspective) influence outcomes such as relational quality. Overall, studies have shown that positive dyadic coping is significantly associated with higher levels of marital satisfaction (Bodenmann, 2005). Although some studies use samples of couples in which both partners are "well," an emerging body of research has explored dyadic coping in the context of illnesses. For example, in a study of couples coping with prostate cancer, C. A. Berg et al. (2008) asked patients and partners to maintain daily diaries in which they recorded bothersome events and appraised their partner's

involvement as uninvolved, supportive, collaborative, or controlling. They found that collaborative coping styles were associated with marital satisfaction. More recently, Badr et al. (2010) examined coping behaviors among women facing metastatic breast cancer and their partners, finding that negative dyadic coping was associated with increased distress for both patients and partners. These studies demonstrate that how people cope within a relational context can influence personal and relational well-being.

A developmental-contextual perspective of couples coping with chronic illness was proposed by C. A. Berg and Upchurch (2007) to explain the process by which dyadic coping unfolds over time and is influenced by a variety of factors. According to the model, both partners' appraisal of a stressor affects both partners' coping efforts, which in turn influence their adjustment (i.e., outcome variables such as psychological and marital adjustment). Moreover, current appraisal, coping, and adjustment affect future appraisal, coping, and adjustment. These processes are also influenced by developmental, temporal, and contextual factors. In short, this framework emphasizes previously underexplored concepts in dyadic coping, including (a) life-span developmental factors, (b) temporal issues, and (c) contextual factors.

First, the model accounts for the fact that dyadic coping may be affected by life-span developmental issues that occur in the marital relationship (C. A. Berg & Upchurch, 2007). Some research has shown that older couples report higher levels of marital satisfaction than younger adults. Additionally, the majority of married older adults are in long-term marriages that, as compared to short-term marriages, are more likely to be marked by stability and collaboration. C. A. Berg and Upchurch posited that such characteristics may increase the incidence with which older adults engage in positive, rather than negative, forms of dyadic

coping. In addition, life-span developmental differences may impact coping and adjustment in that older adults have been shown to adjust better to chronic illness than younger adults.

Second, the model also accounts for temporal issues, including the development of the disease trajectory (C. A. Berg & Upchurch, 2007). Related to the proposition that age may impact coping and adjustment is the tenet that the passing of time may impact coping and adjustment. Obviously, as time passes, people age. However, there are other temporal factors, independent of aging, that may influence coping and adjustment—most notably, the process of moving from the stage of initial diagnosis to other phases of the disease (e.g., treatment, management). The ways in which couples move through different phases of chronic illness have very rarely been explored. C. A. Berg and Upchurch cited practical and methodological challenges as the reason for this paucity of research:

Practically speaking, research with couples experiencing chronic illness is challenging enough, but to add a longitudinal component to follow couples as they identify symptoms, seek a diagnosis and treatment, and live with the management of the illness is especially daunting. (p. 935)

Finally, in their model, C. A. Berg and Upchurch (2007) also proposed that contextual issues such as illness factors and marital quality may influence coping and adjustment.

Regarding illness factors, they noted that couples facing illnesses that require a high level of daily care may require more coping methods. Furthermore, illnesses that impair cognitive and communicative abilities (such as PD) are likely to limit the patient's opportunities to collaboratively cope with his or her partner.

Comforting models of support. In this third subsection on theoretical perspectives, I discuss comforting models of support, which center on a particular dimension of social

support—emotional support or, even more specifically, comforting. Emotional support includes expressions of comfort, affection, and concern that make a person feel cared for (Cutrona & Russell, 1990; Cutrona & Suhr, 1994). A substantial body of work has focused on *comforting* as an important process of emotional support (e.g., Bippus, 2000, 2001; Burleson, 1994, 2003; Burleson & MacGeorge, 2002; Jones & Guerrero, 2001; Stroebe, Schut, & Stroebe, 2005). Burleson and MacGeorge defined comforting as “messages having the goal of alleviating or lessening the emotional distress experienced by others” (p. 395). Comforting behaviors are significant for a number of reasons, including the benefits that they may bring: Studies have found positive associations between comforting and outcomes such as mood and quality of life. In addition, emotional support is an expectation of close relationships, and the act of comforting someone can send an important message of caring as well as friendship or love (Burleson, 1994).

Comforting models typically assess the effectiveness of supportive messages. In 1998, Burleson and Goldsmith offered insight as to why certain message features are important to the comforting process. Drawing from appraisal theories of emotion—which state that negative emotions result not from the existence or occurrence of an external stressor but, instead, from how the stressor is evaluated and appraised—they proposed that comforting can be conceptualized as helping the distressed other reappraise a stressful event. Messages that “display a topical focus on emotion, reflect a descriptive and explanatory orientation, and exhibit sensitivity to face concerns” (p. 273) are likely to create a conversational context conducive to reappraisal—that is, an environment in which the distressed person feels supported and encouraged to elaborate on his or her emotions and attempts at coping. In sum, particular message features can help construct a supportive environment and, in turn, increase the

likelihood that reappraisal will occur, leading to alteration of the distressed person's emotional state.

Earlier work by Burleson (1994) "provides a hierarchical scaling of comforting messages for the extent to which the feelings and perspective of a distressed other are explicitly acknowledged, elaborated, and granted legitimacy" (p. 12). Burleson's comforting model is based on a coding system with three major levels of messages. Messages that fall into the first (i.e., the lowest) level include those that ignore or deny the validity of the hurt person's feelings. The second level of this hierarchy includes messages that have an implicit acknowledgment of the other person's feelings. Messages that are assigned to the third (i.e., the highest) level provide the most explicit acknowledgment and elaboration of the distressed person's feelings. This hierarchical coding system represents a range of sophistication in comforting messages, with level one messages being the least sophisticated and level three messages being the most sophisticated. (Sophisticated messages are also sometimes referred to as person-centered; e.g., Burleson & MacGeorge, 2002.) Burleson (1994) described five attributes of sophisticated messages, noting that they tend to be (a) centered on the listener's feelings and experiences rather than the speaker's, (b) neutral rather than judgmental, (c) focused on feelings, (d) validating, and (e) geared toward helping the listener gain a new level of understanding of his or her feelings.

There is evidence to suggest that, as compared to lower level messages, sophisticated (or person-centered) messages are viewed by the listener as more sensitive and effective (Burleson & Samter, 1985). Also, Jones and Guerrero (2001) found, in an experiment testing the effects of verbal person centeredness (VPC) and nonverbal immediacy (NVI) on perceptions of comforting, that confederates were rated more favorably when they enacted high (versus

moderate or low) levels of both VPC and NVI to a participant disclosing an emotionally upsetting event. These results lend support to Burleson's hierarchical model of comforting by suggesting that using person-centered messages plays an important role in being perceived favorably during comforting episodes. Although such results are a promising step in understanding features of comforting messages, further work is needed. In particular, the role of the situation (i.e., attributes of the problem or stressor being discussed) is not well-understood in this model: It is plausible that the importance of a message being sophisticated or person-centered is dependent upon the situation, yet this model has been tested using only a very limited numbers of stressors. (For example, it is possible that it is useful to legitimate and elaborate a person's feelings about a stressor over which he or she has no control, but that it is not as helpful for a controllable stressor.)

A normative/rhetorical perspective on support. In this final subsection regarding theoretical perspectives, I focus on an approach that Goldsmith (2004) recently proposed for studying social support. In discussing the mixed findings regarding outcomes of enacted support, Goldsmith stated, "Many of the problems and disappointments researchers have encountered in studying enacted support have come about because we have tried to understand communicative phenomena without attention to communicative processes" (p. 24). In an effort to improve this area of research, she explicated a normative/rhetorical approach to the study of social support that centrally features communication. She outlined four assumptions inherent in her conceptualization of enacted social support as communication, including (a) enacted support has meaning; (b) social practices and processes allow for shared meaning; (c) context affects how support is enacted and interpreted; and (d) support is rhetorical in nature. These assumptions are

described next, followed by a discussion of research stemming from this normative/rhetorical perspective regarding dilemmas of communicating support.

The first assumption—that enacted support has meaning—refers to the idea that support is communicated in interaction, evaluated by participants, and assigned meaning (Goldsmith, 2004). Some research has focused on *helpfulness* as a dimension of meaning, resulting in typologies of support attempts that recipients have labeled as helpful versus unhelpful. For example, among bereaved individuals, allowing cathartic expression was described as helpful whereas giving advice was described as unhelpful (Lehman, Ellard, & Wortman, 1986). Although studies on helpful and unhelpful support offer important contributions to the social support literature, there is a need for research that goes beyond typologies and explores the processes that led to those evaluations. That is, research on social support should examine *why* certain messages or interactions are viewed as supportive or unsupportive (Goldsmith, 1992, 2004; Goldsmith & Fitch, 1997).

The second assumption of Goldsmith’s framework is that social practices and processes sometimes make it possible for people to share interpretations of messages. Social practices are typical patterns of communication that allow people to understand or anticipate what is occurring during a conversation; for example, people usually recognize when someone is giving them advice because elements of the interaction likely resemble other advice-giving scenarios they have previously engaged in or witnessed. Similarly, social processes, which refer to the framing of a conversation, may also help people make sense of an interaction. Social processes include the way a person refers to a stressor (e.g., “yours” versus “ours”) as well as metacommunicative techniques (e.g., “I know this isn’t an easy topic to discuss, but I’m so glad that we can talk like this”). Although social practices and processes often lead participants in an interaction to come

to similar interpretations, there are many cases in which people attribute different meanings to the same communicative act. For instance, a number of studies have found that support providers and recipients sometimes provide disparate accounts of enacted support, which may be due to a variety of reasons including differences in perception or memory (Goldsmith, 2004).

Goldsmith's third assumption is that support is enacted and interpreted differently depending on the context. Contextual factors include the environment and conversation that the support is located within as well as the relationship between the participants in the interaction (Goldsmith, 2004). These variables may influence how support is perceived; for example, unsolicited advice given to an employee by a boss may be viewed as an assertion of power, whereas advice given to a friend who is grappling with a weighty decision might be seen as a caring gesture that signals solidarity. In a broader sense, the sociocultural environment can also affect the meanings attributed to communication in that people learn how to evaluate and interpret language through their experiences in social groups (Goldsmith, 2001, 2004). Thus, it is important to study social support in specific populations and situations in order to understand the meanings ascribed to support in a particular context (Goldsmith, 2004).

Finally, the fourth assumption underlying this approach is that social support is rhetorical in nature. In the tradition of O'Keefe and colleagues (O'Keefe, 1988; O'Keefe & Shepherd, 1987), Goldsmith (2004) views communication as a rhetorical tool through which participants play a role in constructing the situation; for example, a person may create a warm atmosphere and imply a close relationship by communicating advice with great compassion and concern. In addition, Goldsmith's framework is grounded in research that examines communication as an interaction in which participants aim to accomplish task, identity, and relational goals (Clark & Delia, 1979). The effectiveness of a message, and the way that a person responds to a message,

can be influenced by the identity and relational meanings implied by the speaker while he or she communicates a task (Caughlin et al., 2009; O’Keefe, 1988; O’Keefe & Shepherd, 1987).

Balancing these multiple goals, however, can be difficult (Goldsmith, 1992, 2004; Goldsmith & Fitch, 1997). It may, for instance, be challenging for a person to give advice without appearing bossy and risking relational strain, or to offer tangible aid while also protecting the other’s identity as self-sufficient. In fact, dilemmas like these drive Goldsmith’s normative/rhetorical approach to studying support, which “is characterized by a focus on how different ways of carrying out the same task (i.e., coping assistance) may be better or worse at adapting to these multiple purposes as they arise in particular situations” (Goldsmith, 2004, p. 47).

In sum, through a series of four assumptions, Goldsmith (2004) conceptualized social support as meaningful, situated action that can be evaluated by the degree to which it attends to the multiple goals of the participants in the interaction. Through her normative/rhetorical perspective, she maintains that, rather than simply reporting frequencies of strategies, research on social support should aim to explore the complexities of the communicative processes and circumstances under which social support is helpful or dilemmatic.

Although there are a growing number of recent studies influenced by Goldsmith’s normative/rhetorical perspective on the dilemmas of social support, some work predating this theoretical approach also acknowledged the existence of dilemmas in social support. For example, Albrecht and Adelman (1987) described a set of problems that they posited were associated with seeking and providing support. They noted that support seekers may sometimes face dilemmas related to impression management (e.g., coming across as “needy”); identity issues (e.g., viewing oneself as incompetent); feelings of helplessness that may evolve into a self-fulfilling prophecy; costs to their relationships; and difficulties in managing strong and weak

ties. Providing support might bring problems associated with the depletion of resources; “contagion effects” (i.e., the risk of personal distress as a result of being around high levels of stress); and uncertainty related to potential relational problems of providing support. This work, and other studies also recognizing potential difficulties in the exchange of support (e.g., Coyne, Ellard, & Smith, 1990; Silver, Wortman, & Crofton, 1990), contributed to the social support field by calling attention to some costs and complications of support. Nonetheless, Albrecht and Adelman acknowledged that further investigation and theoretical development regarding dilemmas within the communication of support was needed. They asserted, “. . . [T]he lack of attention to how [supportive] relationships are constrained presents a critical gap in our knowledge about the process of communicating social support” (p. 253). This early work on dilemmas drew attention to the need for additional research.

Goldsmith and colleagues have aimed to fill that gap by examining dilemmas of support through the theoretical lens of a normative/rhetorical framework (Goldsmith, 2004; Goldsmith & Fitch, 1997). Much of Goldsmith’s work on dilemmas has been in regards to a particular kind of support—advice. For example, through analysis of advice episodes and interviews, Goldsmith and Fitch named three dilemmas related to the provision and receipt of advice. First, advice may be interpreted by the recipient as helpful and caring or as an unwanted intrusion. Second, the advice provider may face a difficult decision about whether to be supportive and agree with the recipient’s perspective or to be honest (which could entail expressing disagreement with the recipient). Third, the recipient might be torn between wanting to convey respect for the advice giver by following his or her advice and wanting to maintain autonomy and make a decision independently.

Dilemmas of advice such as these represent situations in which it is difficult to balance task, identity, and relational goals. Goldsmith (1992, 1994, 2004) turned to P. Brown and Levinson's (1987) politeness theory as a useful framework for thinking about the many different ways advice can be communicated. The task of giving advice in general has the potential to threaten the recipient's positive face (the self-image a person wants to project in a situation) and negative face (the desire not to be imposed on), with varying strategies being more or less face-threatening. For example, the most face-threatening strategy is a bald on-record approach, in which the advice is given plainly and without any form of redress (e.g., "You need to exercise"). In comparison, the least face-threatening strategies entail not giving the advice after all, or using an off-record approach, in which the advice is hinted at rather than directly given (e.g., "Gosh, what a beautiful day for getting out and doing something active!"). Each strategy has advantages and disadvantages, and carries different connotations for task, identity, and relationship. For instance, as compared to one of the more polite strategies, giving advice that is bald on-record is a more efficient way of completing the task. In addition, it may, in some cases, imply a close relationship (e.g., one in which directness is tolerated or even appreciated). Conversely though, bald on-record advice might represent a lack of attention to identity and relational implications and result in the recipient feeling hurt and intruded upon.

Although dilemmas related to supportive communication, like advice, may occur in everyday interactions among any population, there are particular benefits to studying social support among people coping with health problems. That is, studying support in health contexts may contribute to interventions that facilitate coping for patients and their loved ones. In this vein, several scholars have recently taken a normative/rhetorical approach to studying communicative dilemmas in health contexts.

In particular, the intersection of social support and uncertainty management has been examined from a normative/rhetorical perspective in the contexts of both HIV/AIDS and transplantation. Brashers, Neidig, and Goldsmith (2004) found that supportive others can help people living with HIV or AIDS manage their uncertainty by aiding in information seeking and avoiding, lending tangible assistance, encouraging skill development, giving affirmation or acceptance, allowing cathartic expression, and facilitating reappraisals or shifts in perspective. In addition to facilitating uncertainty management, however, social support may also entail costs (i.e., detrimental outcomes) and complications (i.e., disadvantages of support that interfere with uncertainty management). Participants reported costs of support related to losing the feeling (or appearance) of being in control, and experiencing fear or loss when a member of a peer support group dies or becomes more ill. Complications of support may include having different goals for uncertainty management than support providers (e.g., being presented with information despite wanting to maintain uncertainty), experiencing relational uncertainty, and being burdened by the uncertainty of supportive others. Brashers et al. also identified several strategies for managing these dilemmas of support, including being a self-advocate, reframing others' failed attempts at support, recognizing and accepting that not all relationships are supportive, avoiding potentially distressing social interactions (e.g., peer support groups), carefully choosing only certain people to be sources of support, and establishing guidelines or boundaries for support (e.g., regarding others' involvement in health care decisions).

More recently, Scott, Martin, Stone, and Brashers (2011) also took a normative/rhetorical approach to studying social support as uncertainty management, but did so in the context of individuals who had received, or were waiting for, an organ transplant. Transplant patients reported that others communicated support by enacting instrumental assistance, serving as

sources of validation, introducing other perspectives, providing information, and sharing normalizing experiences; however, support was sometimes accompanied by costs and complications related to the difficulty of asking for help, experiencing relational uncertainty, feeling obligated to support providers, and being reminded of the transplant. Participants also described strategies for responding to these complications, including not seeking support or only seeking it strategically, and reappraising others' unhelpful support attempts to frame them more positively.

In addition, conversations about health-related issues have been explored from a normative/rhetorical perspective in two specific contexts: women dealing with fertility challenges and couples coping with cardiac problems. Bute (2009) interviewed women who were dealing with fertility problems, and found that they attributed various meanings to the questions others asked them related to infertility. Different women reported interpreting requests for information as a welcome expression of caring and an invitation to talk, an insensitive gesture, an identity-threat, a rude intrusion on a highly personal topic, and a representation of society's expectations for women to have children. Although social support was not the explicit focus of Bute's study, these findings have implications for supportive communication. In particular, the varied meanings attributed to asking about infertility may create dilemmas for supportive others who want to communicate concern and interest for a loved one dealing with a fertility problem by asking questions, but who fear that the meaning behind their questions may be misinterpreted.

Goldsmith et al. (2006) also examined varying attributions and dilemmas resulting from conversations about lifestyle changes, but focused their investigation on communication occurring between members of a couple in which one partner has undergone cardiac surgery. Based on interviews with patients and partners, Goldsmith et al. identified three dilemmas. First,

communicating about lifestyle modifications may be viewed as a partner's efforts to control, pressure, or criticize the patient. Second, expressions of caring may be perceived positively, but also can carry obligations for the patient (e.g., to talk or to follow advice). Third, talking about lifestyle changes may represent an unwanted reminder of the illness, which can interfere with a patient or partner's transition back to "normal life." In sum, results of these normative/rhetorical studies demonstrate that communication can have multiple meanings that may lead to dilemmas.

In the following section, I move from the presentation of theoretical perspectives and their relevant findings to a focus on the literature regarding social support in the context of PD. After reviewing the extant research, I provide a rationale for why I selected a normative/rhetorical approach for the current project on couples coping with PD.

Social Support and PD

There is little research regarding social support and coping in PD. In fact, Schreurs et al. (2000) asserted, ". . . [I]n the light of the extensive literature on adaptation processes to chronic disease . . . the paucity of studies on coping and social support in PD is striking" (p. 109). To begin, the relatively small number of studies that have explored coping in this population generally have measured the coping efforts of the PWP (rather than the dyad), typically finding active coping (versus passive avoidance) to be associated with decreased depression; however, the direction of this relationship has not always been clear because most studies have been cross-sectional (Schreurs et al.).

Additionally, the role of social support in coping is not well-understood in this context (McComb & Tickle-Degnen, 2005; Schreurs et al., 2000). Some research regarding PWPs has demonstrated a positive association between either social support and better functioning (e.g., less depression) or dissatisfaction with support and distress (Brod et al., 1998; Fleminger, 1991;

Simpson, Haines, Lekwuwa, Wardle, & Crawford, 2006). Conversely, other studies have produced mixed findings or, in some cases, a lack of evidence regarding the relationship between social support and positive outcomes (Ehmann, Beninger, Gawel, & Riopelle, 1990; McComb & Tickle-Degnen; Schreurs et al.). For example, in a study by McComb and Tickle-Degnen, the less social support that PWP's reported receiving, the more they reported feeling stigmatized. Paradoxically though, among this same population, a PWP's perception of having more problems with social support was associated with less bodily discomfort. Furthermore, in a study by Schreurs et al., there was no significant relationship between social support and PWP's quality of life. Finally, Ehmann et al. found that social support was not associated with decreased depression.

A possible explanation for the discrepancies in this body of literature is that the measures of social support are sometimes overly simplistic and might be difficult for patients to interpret uniformly. In fact, McComb and Tickle-Degnen (2005) acknowledged that the three-item scale utilized in their study to assess patients' perceptions of social support may be problematic: "The findings suggest that social support is a complex idea that is not easily measured in current, standard quality of life questionnaires for Parkinson's disease, such as the PDQ-39" (p. 58). Indeed, it seems unlikely that the questions—which ask participants to rate how often in the past 30-days they have had problems with their close relationships, and how often they have received the support they "needed" from others—can capture the intricacies of support. For example, if a PWP's partner has provided him or her with the tangible assistance needed to get through the day, yet done it in a way that is disparaging or guilt-inducing, has the patient received the support he or she "needed?"

Even fewer studies have examined the role of social support in the experiences of partners of PWPs. In one such study (E. Miller et al., 1996), social support experienced by partners was not related to their level of distress. Social support was operationalized as, the number of people outside the carer's immediate household that he/she had been in contact with over the previous two weeks. Such contacts would include visits to or from friends or relatives and contacts with neighbors, as well as more casual events like chatting to the milkman. (p. 264)

Because this network approach to studying social support does not attend to the quality or appropriateness of support, these results simply point to the need for more research.

Rationale for Utilizing a Normative/Rhetorical Model

There is a lack of previous research that explores challenges and dilemmas of support in the context of PD, and I aimed to contribute to a greater understanding of this area by developing a normative/rhetorical model of social support for couples coping with PD. Although the other theoretical approaches I have reviewed within the second part of this chapter (optimal matching, dyadic coping, and comforting models) also stem from a communicative/interactional perspective, I selected Goldsmith's (2004) normative/rhetorical approach as the most appropriate framework for the current project for several reasons. First, a normative/rhetorical approach features the *quality* of support as a central area of investigation (Goldsmith). This is a significant advantage over theoretical perspectives like optimal matching models or the coping congruence approach within the dyadic coping framework, which assess other variables (i.e., the fit between the stressor and the situation, or the congruence of the coping styles of members of a dyad) at the exclusion of the quality of support. Despite the fact that more recent studies of dyadic coping (e.g., Bodenmann et al., 2006) have begun to explore the quality of support by labeling

“positive” and “negative” forms of dyadic coping, they still fall short of explaining the communicative processes that contribute to these evaluations; an assessment of only the type of support or coping occurring will not lead to an understanding of *why* certain support is helpful or not. Second, a normative/rhetorical framework is a fitting model for a study of couples coping with PD in that it takes context into account by acknowledging that communication is situated (Goldsmith), yet it is a general enough framework that it can be adapted to enacted support of any type (unlike comforting models of support which are appropriate lenses for the enactment of only a certain type of aid—emotional support). Finally, the idea that the effectiveness of a supportive message is a function of task, identity, and relational implications is an important contribution of a normative/rhetorical perspective that can help explain the variable meanings that people attribute to supportive interactions (Goldsmith). That is, this perspective recognizes that support is evaluated not just on the basis of fulfilling a particular task (e.g., providing assistance in getting dressed) but also on what is communicated about the identities and relationship within the interaction.

The project’s emphasis on coping with PD in a relational context is valuable due to the paucity of previous research in this area (Schreurs et al., 2000); there is a need for research that identifies the circumstances and processes through which support is communicated effectively or ineffectively. Because the meanings of social support vary by context, it is especially useful to study social support in particular populations and situations (Goldsmith, 2004). More specifically, as mentioned in the opening chapter of this dissertation, there are theoretical and practical benefits to developing a normative/rhetorical model of social support in the context of couples coping with PD. From a theoretical standpoint, explicating population-specific models contributes to an understanding of the communication of social support by enabling researchers

to assess similarities and differences across contexts (Goldsmith). In a practical sense, although all couples facing chronic illness are bound to encounter challenges, some seem to adapt to these difficulties better than others (e.g., C. A. Berg et al., 2008). Studying how people cope with PD in a relational context can illuminate what PWPs and their partners perceive as adaptive and maladaptive ways of dyadically managing stressors related to the disease. Thus, results of this study can be used to inform the creation of interventions and approaches to health care that offer insight about appropriate and effective support strategies for this population; “[c]ommunication scholars are well-positioned to act as experts on the contents of the communication ‘black box’ in social support interventions” (Goldsmith & Brashers, 2008, p. 327).

Research Questions

To accomplish the aforementioned specific aims of (a) describing the ways in which PD affects not only the PWP, but also his or her partner and the relationship, and (b) examining how PWPs and their partners cope with these changes via social support, two research questions were posed. Each research question explored the *perspectives* of PWPs and their partners. Therefore, the results of this study represent PWPs’ and partners’ perspectives regarding their experiences of psychosocial issues and social support.

Psychosocial Challenges and Relational Issues Experienced by PWPs and Partners

RQ1a: According to PWPs and partners, what psychosocial challenges do PWPs experience as a result of the disease?

RQ1b: According to PWPs and partners, what psychosocial challenges do partners experience as a result of the disease?

RQ1c: What relational issues do PWPs and partners report experiencing as a result of the disease?

Communication of Social Support Within Couples Coping with PD

RQ2a: According to PWPs and their partners, in what ways do they communicate social support to one another?

RQ2b: What costs and complications do PWPs and their partners attribute to the exchange of social support?

RQ2c: What strategies do PWPs and partners perceive as effective in managing costs and complications of support, and why?

CHAPTER THREE: METHODS

Results of this study are based on 44 individual, in-depth interviews, including 21 PWPs and 23 partners. In this chapter, I begin by providing an overview of general data collection considerations for an interview study such as this one, along with a rationale for why interviewing was an appropriate method for this study. Then, I describe the study's recruitment methods and criteria, data collection procedures, participant characteristics, and data analysis.

Considerations for Data Collection: Interviewing

The decision of how to collect data is a crucial one for any researcher because, as Charmaz (2006) asserted, “*how* you collect data affects *which* phenomena you will see, *how*, *where*, and *when* you will view them, and *what* sense you will make of them” (p. 15). A researcher must carefully consider, therefore, which method fits best with the particular questions that he or she is interested in studying. Interviews are a logical choice for a researcher interested in gaining an in-depth understanding of a person's perspective. Patton (2002) explained, “Qualitative interviewing begins with the assumption that the perspective of others is meaningful, knowable, and able to be made explicit. We interview to find out what is in and on someone else's mind, to gather their stories” (p. 341). Utilizing this method involves selecting a sample, deciding what type of interviews to conduct, and considering the role of the interviewer.

Sample

Most interview studies rely on nonrandom sampling strategies. These sampling methods may be purposeful (e.g., selecting deviant or extreme cases of a phenomenon) or based on convenience (e.g., including those participants who are easiest or last expensive to recruit; Patton, 2002). A researcher might also use a combination of strategies. For example, in a previous study about PD (S. C. Martin, 2010), I recruited participants based on a combination of

convenience and snowball sampling. In snowball sampling, participants provide the contact information of the researcher to others whom they feel might be interested and eligible for the study (Babbie, 2004). I began by advertising the study in two community publications and passing out flyers at a local PD support group. Participants recruited via these initial sampling techniques often passed along information about the study to other PWPs who might be interested in participating. It is important to recognize the limitations of any particular sample in order to contextualize the results of a study. For instance, the aforementioned sample is unlikely to include individuals who have very advanced stages of PD; the physical and mental impairments of PD are likely to prevent individuals in the advanced stages of the disease from being capable of participating in a study.

An issue closely related to how to recruit participants is the number of participants to include in a sample. Experts in qualitative methods seem to agree that there is no “magic” number. Patton (2002) explained, “Sample size depends on what you want to know, the purpose of the inquiry, what’s at stake, what will be useful, what will have credibility, and what can be done with available time and resources” (p. 244). Instead of a focus on a certain number of participants, a commonly cited criterion is that “enough” participants have been included once data reaches a level of saturation or redundancy (i.e., no new information is being presented; Lincoln & Guba, 1985; Patton; Seidman, 2006).

Types of Interviews

There are three different types of interviews generally conducted in qualitative research, each with a varying degree of structure (Patton, 2002). The least structured type, the *informal conversational interview*, “offers maximum flexibility to pursue information in whatever direction appears to be appropriate, depending on what emerges from observing a particular

setting or from talking with one or more individuals in that setting” (p. 342). This type of interview typically occurs when the researcher is engaging in fieldwork (e.g., observing a population of interest) and is sometimes referred to as an *ethnographic conversation* (Baxter & Babbie, 2004). Questions are not predetermined but, instead, arise as a result of the researcher’s observations and interactions in the research context. For this reason, different questions might be asked of each participant. For example, in a study I conducted with other graduate students as part of a qualitative methods course, we created, implemented, and evaluated a program for older adults (Carnett, Goss, Rhoades, Yang, & Zhou, 2008). The program, which was designed to provide residents at a local nursing home with opportunities for companionship and enrichment, entailed a series of activities each focusing on a different aspect of wellness. During each activity, members of the research team conducted several informal conversational interviews with residents participating in the program. Topics generally focused on leisure activities and residents’ perspectives regarding the program. Being able to adapt the interviews (e.g., length, topic) to each individual participant was important considering that residents ranged widely in their interest levels as well as cognitive and physical abilities. Although this flexible format is an advantage of informal conversational interviews, a corresponding disadvantage is that data collected in this unsystematic manner may be difficult to organize and analyze (Patton).

In contrast, the most structured type of qualitative interview is the *standardized open-ended interview* (Patton, 2002). In this approach, the researcher writes a detailed list of questions (and follow-up questions) prior to the interviewing phase. The expectation is that, during the interviews, questions will be read to each participant in the same order and exactly as written. The justification for the rigidity of this approach is “to be sure that each interviewee gets asked the same questions—the same stimuli—in the same way and the same order, including standard

probes” (p. 344). This can be particularly useful when there are multiple interviewers for a study and there is concern for consistency across all interviews. That is, in interview studies, the interviewer is the “instrument,” and having a strict protocol to follow can help improve reliability. Another advantage of the standardized open-ended interview is that, because the interviewer does not deviate from the list of questions, responses are likely to be focused, saving time in terms of both interviewing and analysis. Conversely, a disadvantage of this approach is that it does not allow the researcher to pursue lines of inquiry that emerge during the interview phase. Furthermore, by asking all participants the same questions, the researcher loses the opportunity to probe individuals about aspects of their particular experience (Patton).

A third type of interview, the *interview guide approach*, is more focused than an informal conversational interview but less structured than a standardized open-ended interview (Patton, 2002). This approach is sometimes referred to as semistructured (e.g., Baxter & Babbie, 2004). Prior to this type of interview, the researcher creates an interview guide containing a list of questions or topics that he or she wants to investigate. During the interview, the interviewer refers to the guide and focuses on the issues listed, but is not restricted to the particular wording or order of the questions; “the interview guide provides topics or subject areas within which the interviewer is free to explore, probe, and ask questions that will elucidate and illuminate that particular subject” (Patton, p. 343). Thus, like an informal conversational interview, the interview guide approach offers the strength of flexibility. Furthermore, like a standardized open-ended interview, this approach has the advantage of focusing on certain topics, making data collection and analysis more systematic. These assets proved to be helpful in a study I conducted with Stone, Scott, and Brashers (S. C. Martin, Stone, Scott, & Brashers, 2010; Scott, Martin, Stone, & Brashers, 2011). We used an interview guide approach to explore the experiences of

organ transplant patients. We found that it was important to refer to the interview guide during each interview to ensure that we asked all participants about the same general issues (e.g., uncertainty, social support, information-seeking/avoiding); however, we also discovered that many interesting findings emerged as a result of letting participants speak freely within those areas of inquiry (i.e., not constraining their responses only to those fitting specific questions). For example, the topic of one article published out of these data focuses on how uncertainty changes across the trajectory of transplantation (S. C. Martin et al.). Although our interview guide included general questions about uncertainty, it did not specifically address this construct in a temporal way; instead, these data emerged as a result of covering certain topics but allowing flexibility within those discussions.

An interview guide approach can be utilized by researchers conducting not only one-on-one interviews, but also focus groups. A *focus group* is defined by Patton (2002) as “an interview with a small group of people on a specific topic” (p. 385). It is similar to an individual interview in its goal to elicit perspectives, but differs in that people get to hear, and react to, one another’s responses. In fact, one of the advantages of a focus group is its interactive nature. People tend to enjoy its inherent social aspect and may be able to recall experiences relevant to the interviewer’s questions more readily after hearing others’ responses. Other advantages of focus groups are that they are effective in terms of cost and time; this type of interviewing allows a researcher to obtain the viewpoints of a group of participants in a relatively short amount of time (Marshall & Rossman, 2006; Patton). Focus groups, however, do have several disadvantages as well. For example, confidentiality cannot be protected in focus groups; there is no guarantee that participants will not disclose what they hear to others outside of the group. Another disadvantage is that, compared to one-on-one interviews, each participant has a more limited response time.

This difficulty can be exacerbated if a participant tries to take control of the conversation for a disproportionate amount of time; in such cases, the researcher should act like a moderator and redirect the questions to other participants. Finally, some participants may not feel comfortable sharing their views in front of others, particularly if they are different than what the majority of other participants have expressed (Patton).

Role of the Interviewer

The primary task of an interviewer is to facilitate the conversation in order to gather data. This entails asking thoughtful questions, listening carefully, and paying attention to issues of rapport and neutrality. There are many different ways that an interview question might be worded. Questions should be clear, neutral, open-ended, and focused on a single idea (Patton, 2002). Along with how questions are worded, an interviewer should also consider the sequencing of questions. For example, an interviewer might begin with non-controversial questions that participants are likely to find easy to answer before moving on to more sensitive questions (Ryan, Coughlan, & Cronin, 2009). In addition, an effective interviewer is one who actively listens to each participant. In fact, Seidman (2006) called listening “the most important skill in interviewing” and advised interviewers to “listen more, talk less” (p. 78). The interviewer should allow the interviewee to talk at length, offering follow-up questions when needed to facilitate understanding.

Furthermore, the tasks of establishing rapport and maintaining neutrality add complexity to the role of the interviewer. Patton (2002) distinguished between rapport and neutrality, saying, “Rapport means that I respect the people being interviewed, so what they say is important because of who is saying it” whereas “Neutrality means that the person being interviewed can tell me anything without engendering either my favor or disfavor with regard to the content of

his or her response” (p. 365). In other words, establishing rapport has to do with building a positive connection with the interviewee, and maintaining neutrality means that the interviewer does not convey support or opposition of any particular viewpoint. The aforementioned tasks of asking questions and listening are closely related to rapport and neutrality. For example, when an interviewer actively listens and seems truly engaged, rapport is likely to be built as a result of the interviewee feeling respected. Also, when an interviewer asks non-leading questions, he or she maintains neutrality and increases the likelihood that the interviewee will respond genuinely. Other ways of maintaining neutrality are for the interviewer to manage how he or she responds to what the interviewee says (i.e., avoiding positive or negative reinforcement) and to refrain from frequently sharing personal experiences with the interviewee (Seidman, 2006).

Strengths, Weaknesses, and Utility in the PD Context

In addition to the specific advantages and disadvantages of each type of interview discussed, there are general strengths and weaknesses to interviewing as a data collection method. First, weaknesses of this method in general include that it may not always yield detailed or even truthful or accurate accounts. For instance, participants may be shy or uncomfortable, embarrassed by the topic, or simply forgetful, and any of these issues could lead to misinformation or a lack of data. Moreover, the interviewer may be unskilled at asking questions and establishing rapport with participants, thus creating difficulty in eliciting rich data (Marshall & Rossman, 2006). An unskilled interviewer may also introduce bias by asking leading questions or reacting in a judgmental manner to participants’ responses. Pretesting an interview guide, which entails enlisting the expertise of people familiar with the topic of the interview and practicing the questions before actually asking them of participants, can help combat some of these issues (B. L. Berg, 2004).

Conversely, the main strengths of this method are that it can provide in-depth insight into people's perspectives and it allows researchers to investigate phenomena that cannot be easily observed (Baxter & Babbie, 2004; Patton, 2002). I believe these advantages made interviewing a particularly appropriate method for the current study of couples coping with PD. That is, method selection should be driven by the research questions of a study and, because I was interested in learning about the perspectives of PWPs and their partners (including past experiences and conversations that cannot be observed), interviewing is an excellent fit, especially considering the lack of extant research on this topic. Certainly, interviewing is not the only method that could be utilized to gather data regarding people's thoughts; survey research can also be a highly effective way of collecting this type of information. When a researcher seeks detailed responses that are not constrained by a limited number of choices, however, interviewing can be a particularly useful method, as Baxter and Babbie concluded:

Although thoughts and feelings can be assessed through structured questionnaires and surveys, survey research limits individuals' responses to a selection of a number or a phrase as defined by the researcher. When a researcher wants an in-depth understanding of the interviewee's perceptions and feelings in his or her own words, a qualitative interview is the method of choice. (p. 326)

Furthermore, although observing couple's conversations can produce valuable insight about how the dyad interacts, it is typically not possible to "shadow" a couple at length in their private lives to see patterns of interaction (Baxter & Babbie) nor would such observations yield data about how the participants felt. Patton explained,

The issue is not whether observational data are more desirable, valid, or meaningful than self-report data. The fact is that we cannot observe everything. We cannot observe

feelings, thoughts, and intentions. We cannot observe behaviors that took place at some previous point in time. We cannot observe situations that preclude the presence of an observer. We cannot observe how people have organized the world and the meanings they attach to what goes on in the world. We have to ask people questions about those things. (p. 341)

In sum, interviews are an appropriate methodological choice when the researcher seeks in-depth understanding of participants' perspectives; being able to explore thoughts, feelings, and experiences that are not easily observable is a significant strength of this method.

A small number of researchers have utilized in-depth interviews to explore the experiences and coping strategies of PWPs (e.g., Charlton & Barrow, 2002; S. C. Martin, 2010), their partners (e.g., Habermann, 2000), and the dyad (e.g., Birgersson & Edberg, 2004; Hodgson et al., 2004). In planning an interview study about couples coping with PD, an important consideration is whether to interview members of the couple separately or together. Interviews in which members of a couple are interviewed together are appropriate for when a researcher seeks a joint account of a couple's experiences and the way that they collectively present them, whereas individual interviews are suitable for gathering data about each person's perspective. Each type of interviewing context offers distinct advantages and disadvantages. Joint interviews allow members of a couple to react to each other's responses to interview questions, which can provide valuable opportunities for one person to validate, add to, or even correct or modify what the other has said (Valentine, 1999). This could be a particular advantage in a study of couples coping with PD because the disease sometimes leads to memory problems; thus, having a partner present may help a PWP confirm or recall details (e.g., date of diagnosis).

A disadvantage, though, is that if members of a couple express disagreement during an interview or present conflicting accounts of an experience, a researcher may have a difficult time making sense of the data. Other potential disadvantages of joint interviews are that it may be challenging to find a time that works for both members of the couple to be interviewed, and having a partner present may limit a person's willingness to disclose openly (Valentine, 1999). This latter possibility could become very salient in joint interviews of couples coping with PD; for example, a PWP may not want to risk seeming ungrateful by discussing support attempts that the partner has made that have not been helpful. Conversely, interviewing members of a couple separately affords individuals privacy and may make each person feel more comfortable in discussing sensitive topics related to their partners (Hertz, 1995; Valentine).

Methodology of the Current Project

Details about recruitment methods and criteria, data collection procedures, participant characteristics, and data analysis are explicated in the following subsections.

Recruitment Methods and Criteria

Participants were recruited through four venues: (a) by visiting PD support groups in and around Central Illinois; (b) by placing an ad in the local newspaper, the *News Gazette*; (c) by placing an ad in *Eweek*, the electronic newsletter of the faculty and staff of the University of Illinois, Urbana-Champaign; and (d) by using snowball sampling. Inclusion criteria required (a) either having been diagnosed with PD or being the current partner of a PWP; (b) being in a committed relationship with a spouse or cohabitating partner; (c) having been with this same partner since the time of, or before, the PD diagnosis; (d) an ability to speak and read English; and (e) being physically and cognitively able to communicate with an interviewer about his or

her experiences. I screened for these criteria during the initial contact (e.g., during a telephone conversation with the PWP or partner) in the recruitment phase.

Data Collection Procedures

Before data collection began, the study was approved by the University of Illinois, Urbana-Champaign, Human Subjects Institutional Review Board (IRB). Prior to each interview, participants' consent was obtained. To obtain descriptive data, participants were asked to complete a short demographic questionnaire for patients (see Appendix A) or partners (see Appendix B). Both versions of the questionnaire included a PD staging scale that asked participants to evaluate the severity of PD experienced by them or their partner. The scale, developed by Hoehn and Yahr (1967), is one of the most commonly used measures of a PWP's phase. It places PWPs in one of six stages (0-5) based on symptoms of PD (e.g., 0 means that the patient has no visible symptoms of PD, and 5 means that he or she has symptoms on both sides of the body and is unable to walk). On both versions of the questionnaire, numbers were omitted from this scale in an attempt to avoid the possibility of inciting negative emotions (e.g., in PWPs who rate as a 5, the most severe stage). Because some PWPs had difficulty with this completing the questionnaire due to decreased motor skills, the interviewer assisted PWPs in filling out the demographic questionnaire as necessary. At the completion of the interview, each participant received \$25.

Interviews were conducted using a semi-structured interview guide (see Appendix C). This guide was generated from research on stressors related to PD, social support, and coping. A modified version of the same interview guide was used for partners (see Appendix D). The interviews began with questions about the experience of symptoms pre-diagnosis and moved to questions about receiving the diagnosis. Then, the interviews focused on changes related to the

disease, in which participants were asked about the impact of the disease on them, their partners, and the relationship. Specifically, participants were asked if they or their partner had experienced a number of common stressors related to the disease as well as relational changes. Next, the questions focused on the communication between patients and partners about PD before exploring experiences of social support and coping. Finally, the interview schedule concluded with questions about what advice participants would offer others affected by PD and provided an opportunity for additional comments or questions.

I utilized an interview guide approach because it offers flexibility (much like an informal conversational interview). It also has the advantage of focusing on certain topics (similar to a standardized open-ended interview), making data collection and analysis more systematic (Patton, 2002). All interviews were conducted separately (i.e., without the presence of the interviewee's partner). The rationale for this decision was that it could be difficult to talk about some issues (e.g., relational challenges, dilemmas of coping jointly, stressors related to providing support) in the presence of one's partner (Valentine, 1999). Interviews were held at a location convenient for the participant. Most participants, particularly those with limited physical mobility, chose to be interviewed in their homes. Interviews lasted approximately 45 to 150 minutes each.

Participant Characteristics

The final sample was 44 individuals, including 21 dyads and 2 partners whose PWP did not participate (for a total of 21 PWPs and 23 partners). Of the PWPs, 13 (62%) were males and 8 (38%) were female. PWPs ranged in age from 41 to 89 years old, and had an average age of 68. The average time since PD diagnosis was 6 years (ranging from less than 1 year to 26 years). PWPs also varied in how advanced their PD was, based on their self-report using Hoehn and

Yahr's (1967) scale: 0 PWPs reported having "no visible symptoms of PD" (stage 0); 8 PWPs reported having "symptoms on only one side of the body" (stage 1); 3 PWPs reported having "symptoms on both sides of the body and no difficulty walking" (stage 2); 5 PWPs reported having "symptoms on both sides of the body and minimal difficulty walking" (stage 3); 5 PWPs reported having "symptoms on both sides of the body moderate difficulty walking" (stage 4); and 0 PWPs reported having "symptoms on both sides of the body and unable to walk" (stage 5). On average, PWPs were near the midpoint of this scale (2.33). Of the 23 partners in this sample, 15 (65%) were female and 8 (35%) were male. Partners ranged in age from 38 to 84, with an average age of 67. Across the 44 total participants, nearly all ($n = 42$, 95%) reported their racial/ethnic identity as Caucasian. Two participants (1 PWP and 1 partner) identified as African-American. All participants were in heterosexual relationships, and nearly all were married (with the exception of one dyad). Participants reported having been with their partner for an average of 38 years (range 3 to 64 years).

Data Analysis

Interviews were recorded and transcribed verbatim, then analyzed using grounded theory techniques. (In all reporting of results, names were replaced by pseudonyms.) According to Charmaz, "grounded theory methods consist of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories 'grounded' in the data themselves" (2006, p. 2). Grounded theory techniques include open coding and axial coding, which are the interrelated processes of identifying concepts within the data and breaking them into categories by deciphering ways in which they are related. Integral to these processes is the use of constant comparison, in which "each incident in the data is compared with other incidents for similarities and differences" (Corbin & Strauss, 2008, p. 73). Ultimately, the categories delineated through

these comparative processes are integrated and refined into a theory describing a phenomenon (Corbin & Strauss).

Glaser and Strauss (1967) originated grounded theory as a way of “discovering” theory from data (though Charmaz, 2006, has since made the argument that theories are “constructed” rather than “discovered”). This initial iteration of grounded theory emphasized the importance of entering a study without predetermined ideas about how aspects of the data might fit together; according to the earliest versions of this approach, researchers should begin a study without a theoretical framework in mind, meaning that a literature review would not be done until *after* data collection and analysis. In more recent conceptualizations of grounded theory, though, Corbin and Strauss (2008) have asserted that researchers utilizing this method may in fact be informed by previous research and, at times, grounded theory can be used to verify, apply, or extend past conclusions.

In the current project, I utilized this more recent conceptualization of grounded theory (i.e., remaining neutral and open to emergent themes while also acknowledging the influence of existing theoretical frameworks). Throughout the data collection process, notes were taken at the completion of each interview to record constructs and promising lines of inquiry. Using constant comparative methods, the transcripts were carefully read through many times by coders (i.e., myself and a colleague who has also been trained in grounded theory techniques) with the goal of detecting patterns and commonalities. In this process of open coding, identifying terms were added as notes to the transcripts. These terms were continually revised as a clearer understanding of salient constructs developed. Constructs were compared and either grouped together or differentiated. Then, in a process of axial coding, I hypothesized about connections between

concepts (Corbin & Strauss, 2008; Glaser & Strauss, 1967). Finally, I selected quotes to represent each category. Results are presented in the following chapter.

CHAPTER FOUR: RESULTS

The experience of PD brings challenges beyond the physical manifestations of the disease. When PD occurs in the context of a partnership (i.e., marriage or other romantic relationship), both members of the couple are affected. An important way of managing these challenges in a relational context is via social support. Thus, this chapter is organized into two main sections: (a) the experience of psychosocial challenges and (b) coping with these challenges in a relational context via social support.

The first section explicates the multitude of challenges experienced by couples coping with PD. In the second section, participants' reported ways of communicating social support are delineated. Because supportive attempts can have multiple meanings and are not always interpreted as entirely helpful (Goldsmith, 2004), this second section also includes complications and costs of support experienced by participants. These challenges illuminate dilemmas of support and why some support attempts may be perceived as less effective than others. Finally, the strategies that participants described as effective in managing complications and costs of social support are detailed.

Psychosocial Challenges and Relational Issues Experienced by PWPs and Partners

This section begins by describing the psychosocial challenges experienced by PWPs. Then, psychosocial challenges experienced by partners are detailed. Finally, the relational issues that participants discussed occurring as a result of PD are reported. Although challenges related to the PWP, partner, and relationship are each presented in separate subsections, these issues are highly intertwined (e.g., both party's challenges can affect the other person as well as their relationship). This overlapping nature is represented in Figure 1, in which results regarding the

psychosocial challenges and relational issues experienced by PWPs and partners are summarized.

Psychosocial Challenges Experienced by PWPs

The experience of having PD can yield many psychosocial challenges for PWPs. Participants described issues encountered by the PWP related to (a) having to withdraw from, or struggle with, certain leisure activities; (b) having difficulty fulfilling previous roles or tasks; (c) being treated as helpless or ill; (d) experiencing communication-debilitating symptoms; (e) having concerns regarding their public self-presentation; (f) experiencing changes in their sociability or social life; (g) being unable to predict their daily well-being; and (h) feeling uncertain about their disease progression and the future.

Having to withdraw from, or struggle with, certain leisure activities. A significant challenge of PD is that the physical manifestations of the disease often result in the PWP having to give up, or struggle with, certain leisure activities. Participants frequently mentioned traveling, for example, as an activity that has been negatively affected by PD. Carl, a 70 year-old PWP who was diagnosed five years ago, said that although he used to enjoy traveling,

It's just too much hassle with Parkinson's. You have to worry about how your medication translates through the time zones. You have to worry about falling down when you're dragging through the airport pulling your suitcase. And when you're out on the sidewalk, are there cracks in the sidewalk you might fall over? Might you get mugged because you don't look like you're very physically competent? So, one of the things that I've sort of minimized and stayed away from is travel.

For some PWPs, like Carl, PD-related concerns have made traveling seem impractical and unappealing. Other PWPs said they still enjoy traveling, but expect it to become increasingly

difficult as the disease advances. Warren, a 67 year-old PWP who walks with a limp due to the disease, said he has become progressively slower and more easily fatigued since being diagnosed about a year ago. He wondered about how his PD would impact an upcoming trip:

Yeah, [PD has] kind of slowed me down a little bit. We go to Disneyworld every year, and we own a vacation club down there. Last year, I was able to walk around through all the theme parks pretty good. I'm just concerned about this year. . . . I may not be able to walk from one end of a theme park to another real quickly. I'm anticipating trouble, but I don't know. I think the limping, and that kind of thing, kind of tires me out.

Although Warren hopes he will not have to discontinue these annual trips, he acknowledged that he will have to make modifications and stop frequently to rest when walking: “I can only walk maybe 20, 30 minutes before I get tired now.”

In addition to traveling, participants discussed a host of other leisure activities that have become difficult for the PWP as a result of the physical limitations caused by PD. Several PWPs mentioned, for example, no longer being able to throw a baseball or hit a racquetball, and said that they had stopped participating in sports to avoid embarrassment (as also discussed in the later subsection on PWPs’ concerns regarding public self-presentation). Other PWPs recalled having to give up a valued, physically-oriented hobby for safety reasons. Lisa, a 47 year-old PWP, said, “I used to ride a motorcycle for fun. That's probably one of the things I’ve lost, yes. I can't ride a motorcycle anymore. I don't have much of an option, because [PD] affects my left leg. I've had a couple accidents.” Similarly, Barry, a 66 year-old PWP who was diagnosed a year ago and has trouble with balance, described his frustration at no longer being able to engage in outdoor leisure activities that he previously enjoyed: “It's just hard to give up. I'm used to riding horses, and I used to ride motorcycles and I had my ATV [all-terrain vehicle].” Further, he

explained that discontinuing these activities entirely has not been his choice: “I would like to ride horses still a little bit, but [my family] won't let me up on it.” Another PWP, 78 year-old Ken, also said that his family’s concern for his safety has led him to give up a cherished hobby: maintaining a garden plot at a local college. Although he still does yard-work at home now (ten years after being diagnosed), his wife and adult children recently became uncomfortable with the idea of him gardening by himself in a fairly remote spot on the campus:

For years, I've had a garden plot at [the college], worked in it, and I had about two or three falls in the garden plot, out there by myself. The family didn't want me to go out there because I might fall and couldn't get up. So this year, I'm cutting it out, so I had to give that up.

In reflecting on the loss of this hobby, Ken concluded, “Well, Parkinson’s has cut back on my quality of life some.”

Many hobbies that PWPs have to give up, or struggle with, due to PD involve a moderate or significant amount of physical exercise (e.g., gardening, walking); however, some less physically-oriented leisure activities may become challenging as well. For example, concentration difficulties due to PD have led Tina, age 59, to discontinue one of her favorite hobbies: reading. Her husband Ed explained,

One thing Parkinson's has affected in her life is her reading. She used to love to read Stephen King. She can't read anymore. It's not that she can't read. It's that if she's reading an article in the newspaper, by the time she gets halfway through it, she's kind of lost what the first part of the article was. Her train of thought's gone. . . . That's probably one of the biggest things that's bothered her.

The symptoms of PD can make it difficult for the PWP to maintain a hobby that he or she has enjoyed for years, as in Tina's case with reading. At other times, PD may make it challenging for the PWP to continue a relatively new pastime, as described by Ron, a 68 year-old PWP whose symptoms are primarily on his left side: "I took up the cello in recent years; I'm a very bad amateur cellist. I enjoy playing the cello, but my left hand is weak and slow, which makes it hard." He explained that, although playing has become increasingly tricky for him, he continues to play not only because he finds it mentally stimulating, but also because he hopes that the activity may be slowing down further loss of dexterity and strength in his left hand.

Having difficulty fulfilling previous roles or tasks. In addition to certain hobbies becoming difficult due to PD, some non-leisure tasks and roles can be challenging for PWP's to fulfill. Among PWP's who have a job at the time of diagnosis, the issue of whether or not PD will affect their ability to keep working often becomes a concern. Several participants said that PD was a catalyst in the PWP's decision to quit or retire. For PWP's with a position involving physical labor, like 66 year-old Barry, continuing to work may not be a viable option because PD can make it impossible to meet the physical demands of the job: "I feel like guilty of not working, but I know that I can't physically do that for more than two hours at a time." Sharon, a 71 year-old who has had PD for over twenty years, said it was her adult children's concern about her worsening symptoms that prompted her to retire at age 68: "I would maybe have worked another couple of years, but my kids were anxious for me to take a little time." She also indicated that, leading up to retirement, performing her job had become increasingly difficult due to mental symptoms of PD. (Her symptoms have since improved as a result of having Deep Brain Stimulation, a surgery designed to reduce signs of PD, at age 70.) She said, "I think there was a time right before I retired when I had a lot of difficulty communicating, and that affected my

work. My children will tell you that I was never finishing a sentence.” In his interview, Sharon’s husband Paul said, “She would have stayed on working [had it not been for PD], but she got to the point where [she thought], ‘I’m not doing the company justice either.’ And she was old enough she could retire.”

Other PWP’s reported that they continue to work out of necessity, but that they have had to make some modifications due to PD. Greg, a 63 year-old PWP, explained that, in the four years since his diagnosis, PD has induced concentration problems that have affected his job performance: “My focus as I’m working . . . I’ll forget sometimes exactly what I was starting to do and I’ll have to think a second. And that’s been a factor, very noticeable over the last few years. I’m sure that that is related to the Parkinson’s.” As a result, his job takes him longer, and he puts in several extra hours of work at home each evening to compensate. Another PWP, 41 year-old Ray, switched jobs at his company because he felt the stress of his previous position was exacerbating his PD symptoms. His wife Kelly explained,

He did change his job due to Parkinson’s. He was a salesman—very good—he was the top salesman they had. The stress of the job though made the symptoms so heightened, because, if you’ve ever seen a Parkinson’s patient, if they get stressed, or even excited, you will see the symptoms. I mean it really heightens their symptoms. And he felt he really needed to get out of that position, and he took the [other] position, he moved over into that. And it’s very stressful, too—it’s become very stressful, but he is not on a one-on-one basis with vendors, [so] he can control a little bit more when he talks to them. So he kind of has a little bit more control over his timing of when he wants to deal with something. The timing of his medicine is everything to him.

For Ray, switching roles and moving to a less people-oriented position has allowed him to continue to work while coping with PD. Although his current position is not without stress, he now works mostly independently and can plan meetings around his medication, allowing him to avoid interacting with others when his PD symptoms are the worst.

Along with work, participants discussed many other tasks and roles that have been affected by PD. Driving was mentioned by a number of participants as an activity that they either have had to discontinue or do less of out of concern for their own and others' safety. Deb, a 73 year-old PWP who was diagnosed close to three years ago, recalled,

I always drove. I haven't been driving now, and that's a difference. Last time I drove . . . I couldn't hang on to the steering wheel. This hand kept jerking. This leg, it won't always move when I want it to. I said to Larry—I said, “That's it, I'm not going to drive because I'm not going to be one of those people that kills somebody.” So, it has been a year and a half [since I drove].

Deb went on to say that not being able to drive has threatened her identity as an independent woman: “I used to be off driving wherever I pleased. I mean, I was a pretty independent woman. . . . Not driving has made me lose that sense of independence.” Another PWP, 69 year-old Anna, also noted that driving less has made her increasingly dependent on her husband Doug. In addition, she expressed uncertainty about whether she is making the right choice when opting not to drive:

You don't know whether—how many chances to take. You don't know whether it's going to be—like if you're being a chicken or if it's smart to—like the driving thing. Sometimes, maybe that's endangering somebody else, even though maybe I'd be better if I did it more. It's hard to know which is more sensible. I kind of compromise, and I don't usually take

the brave way. I don't want to be, you know, hurting anybody else, either. So, I drive locally, but I don't drive where there's a lot of traffic. I think I've changed—can't decide fast enough to be really safe when I'm out there with big traffic. It takes me longer. I have to think about things. Nobody else is thinking about it. They're going. So that means I'm more dependent on Doug to take me places.

For many people, including PWPs Deb and Anna, driving is linked to independence—and therefore, having to eliminate or reduce driving due to a chronic illness represents a loss of independence and an increased reliance on others.

Participants also listed many household tasks that have become difficult or impossible for the PWP to complete. Some PWPs and partners explained that the PWP had been forced to withdraw from doing projects around the home. Helen said her 80 year-old husband Walt “used to be ‘Mr. Fix-It’” but, because of PD, no longer has the fine motor skills nor the concentration needed to complete home repairs. She recounted one example of this: “He used to be able to do electrical, and our daughter [recently] said one of her lights was out. He said to her, ‘I’ll do it, I’ll fix it,’ and he couldn’t do it, which is frustrating for him.” It seems likely that episodes like this, when recurrent, may alter aspects of an individual’s identity (in this case, by diminishing a perception held by oneself and others that the PWP is a competent “handyman,” or “Mr. Fix-It”). Other participants cited finances as a domain that the PWP has always handled, but now struggles with. Carol, a partner, contemplated the increasing difficulty her 78 year-old husband Ken has with completing their taxes:

It will be interesting to see what we do about the income tax because he has always done that. It’s a laborious procedure, all the medical things and all that sort of—and then it’s a manual sort of procedure; he doesn’t use the computer programs. . . . But he has always

done it. Gosh, it occupied him for a whole month practically. . . . But more and more, I would find errors and I said, “Look, look: You cost us a couple hundred dollars.” Carol concluded that Ken will likely no longer be able to work on their finances at all soon, saying,

That will be another step, I’m sure, in his succession of gradual steps. And that’s a pulling back, that’s a loss—loss would be the word, I suppose, of things you used to be able to do, but can’t. I hate to say it as losing something, but essentially you are. You are retreating from something.

Finally, other routine household chores such as cooking and cleaning were also mentioned by participants as activities that have become challenging for PWPs. Lisa, a 47 year-old PWP who was diagnosed less than a year ago, pointed to a burn mark on her arm and explained why she no longer feels comfortable cooking:

I can't get a grip, and when I do, I drop it. . . . The pan I picked up was a pizza pan in the oven, one of those heavy kind of crock ones, so when I picked it up, I dropped it and my right arm automatically went up in the oven.

As a result, Lisa’s husband Joe has taken over the cooking. As discussed in the later subsection about challenges for partners, shouldering increased responsibility is a common source of stress for partners of PWPs. This shift in tasks can also be challenging for PWPs, who may worry that they are burdening their partners. Anna, a 69 year-old PWP, tearfully recalled a painful memory related to her inability to clean on days she feels unwell due to PD:

One time I heard [my husband Doug]. He was cleaning house or something, and he said, “It's just not fair that it'll always be *me* doing this crap. It's just not fair.” I heard him saying that when we were just learning that I had it.

This incident planted a fear in Anna that Doug might, at times, feel “trapped” with her and burdened as a result of her illness.

Being treated as helpless or ill. Another challenge that PWPs face is being treated as helpless or ill. As discussed in the previous subsections, PWPs often lose the ability to continue previous roles or activities and, in some cases, this can threaten the way they view themselves (e.g., as an independent person). When others treat them as helpless or ill, this can also be an identity threat to PWPs in that they may take it as a sign that people view them as less than capable. Jack, a 47 year-old PWP who was diagnosed less than a year ago, said he wants to be thought of as “just Jack and not Jack with Parkinson’s.” He explained that he resists when others treat him differently because of his illness:

That’s a frustrating point for the whole disease, I think, is when people look at you and think you’re feeble. That kind of gets me in danger. I start doing things that I probably shouldn’t do. I saw another friend that I hadn’t seen in a while. . . . My brother and I stopped in to see her because we happened to be in the neighborhood, and we hadn’t seen their new house. My brother said, “Could we get a quick tour?” and she said yeah. He said, “Should we take our shoes off?” She said, “Well, you don’t really have to. Jack, I know that might be really difficult for you.” I was like, “No, it’s not; I have *no* trouble.” I stood there on one leg and took my shoes off just to show her I could do it. And then I got a little wobbly. [laughs] But, I was like, “I’ve got it; I did it. There you go!”

Although others may have good intentions when being mindful of Jack’s PD, he does not like this type of treatment because it threatens his identity as “just Jack” (i.e., his pre-PD self). He responds to this threat by attempting to show others (and, perhaps, himself) that he is still capable of performing whatever task is at hand.

Other PWPs, like 71 year-old Wanda, said that being treated as helpless or ill can impinge on their sense of independence. She described a friend who has been “very doting” since she was diagnosed two years ago, saying,

It’s like when I go to her house, I’m waited on hand and foot. I’m really uncomfortable with that. I’m uncomfortable with people trying to hang onto me. I feel like when I need that, I’ll say something. Independence is very important to me.

For Wanda, being self-reliant is a valued part of her identity—and being treated differently because of PD infringes on this aspect of herself.

Experiencing communication-debilitating symptoms. PWPs also commonly face the challenge of having communication-debilitating symptoms. Although communication-debilitating symptoms can be frustrating in and of themselves, they can also contribute to other psychosocial challenges for PWPs (as will be discussed in the later subsections on concerns regarding public self-presentation and changes in sociability or social life). Participants cited numerous ways that the PWP’s physical ability to communicate has been compromised, particularly as related to memory and concentration, volume, clarity, nonverbal expressiveness, and writing.

Memory problems can diminish the PWP’s ability to recall names or words during conversations. A partner, Alice, said that her husband Carl, who was diagnosed five years ago at age 65, has recently begun forgetting names:

The reason that it’s so apparent is because, unlike me, he has a memory that’s just incredible. Everybody has always mentioned that. He can remember things when he was two. He does not forget those things. And he has not forgotten them; he still has that memory. [But] lately, he can’t remember names.

Other PWPs struggle, at times, with not just names but common words. Lisa, a 47 year-old PWP, explained that, sometimes, even though she knows what she wants to say, she will forget an “everyday type of word” that seems crucial to the point she is trying to express. Her husband Joe noted how frustrating this can be for her:

She has the thought in her head, but she can’t get it out. . . . That’s the worst thing that upsets her, is she can’t get her words out. She’s a big talker, so that makes her mad.

Another PWP, 59 year-old Tina, also has started having difficulty thinking of words at times and has to turn to her husband Ed for help: “Sometimes, I can’t recall the word—let’s say the word ‘recover,’ and I have to say, ‘Ed, what’s that word for whatever?’” She went on to say,

Dr. [name omitted] explained it to me like this: “Parkinson’s, you ask them the question.

They say, ‘Just a minute, I’ve got to think of the word.’ And Alzheimer’s they say, ‘What was the question?’” So that has made me feel a little more comfortable, and Ed, too, that it is just Parkinson’s-related.

Tina and her husband were relieved to hear her neurologist’s reassurance that her memory problems are not indicative of Alzheimer’s disease because, she explained, the idea of her eventually developing “serious mental symptoms” (e.g., severe memory lapses more commonly associated with Alzheimer’s disease) scares them more than the prospect of physical deterioration.

In some cases though, PD can in fact lead to memory and concentration problems that go beyond just forgetting a single word or name at a time. Trouble with memory and concentration, for example, can become especially apparent when the PWP has difficulty following a conversation or loses a thought mid-sentence. Of her 66 year-old husband Barry (who was diagnosed with PD about a year ago), Ruth said, “He will start talking about something and it’s

like he can't think of the next word, and when he is thinking of that, he loses his whole train of thought. So, it is difficult for him." Another partner, Edna, described a similar occurrence with her 73 year-old husband Eugene, who was diagnosed with PD ten years ago: "He got to the point where he couldn't communicate with me. He would start to say something, get maybe two words out and he couldn't remember what he was going to talk about." She went on to say that PD medications have since helped his memory and concentration to some extent, but that communication is still a significant challenge for him that has led him to talk less.

Language production can be difficult for PWP's not only due to memory and concentration problems, but also because of challenges related to the volume and clarity of their voice. Many participants reported that the PWP's voice has gotten quieter. A partner, Pam, said of her husband Jack's PD, "Definitely it's affected his volume. When he talks, it's like, 'What?' You almost have to lean in. He's very soft." In addition, participants noted changes in the clarity or quality of the PWP's speech—for example, calling it "garbled," "slurred," or "much rougher." Allen, an 84 year-old PWP, said,

I kind of mush my words. They're not very clear. Sometimes, I have to repeat. If I go to the drive-in eating place, they can't understand me. I have to keep repeating. All of a sudden the [drive-in speaker] thing seems to shut off on me. It's like it's closed down. Another PWP, 73 year-old Deb, also struggles with people being able to understand what she is saying at times. She explained how PD has begun impeding her speech:

I have trouble controlling my tongue now, and that causes a problem talking and I just started this summer with trouble—I don't swallow like I did, so I have saliva, but I breathe through my mouth most of the time, and so my mouth is dry. It doesn't make any sense, but that's the way it is.

Participants also reported changes in the PWP's ability to be nonverbally expressive. Often, partners notice this change more than PWPs themselves do. When listing PD symptoms that she has observed in her husband, 78 year-old Ken, Carol said,

I suppose [he has] the inanimate facial expression that doesn't react—that doesn't seem to get involved in the conversation. . . . You keep the same facial expression, it's like you're not reacting to what's going on around you, that sort of thing, so that was one of the earliest [symptoms].

Similarly, another partner, Alice, said of her 70 year-old husband Carl, "It's like he's got a sour face. I'll just say, 'Smile.' I don't think that he realizes that he has this expression on his face . . . and if you don't realize it, that's the way you look." Reiterating the idea that it can be difficult to recognize this facial "masking" in oneself, 59 year-old PWP Tina said, "The doctor says that I do have it. But I don't know. I can still laugh, but I can't pretend to laugh. I've lost that ability to smile in a photo. That phony smile—I can't do that anymore."

Finally, PD can also affect communication outside of the realm of conversation by diminishing a PWP's ability to write legibly. Walt, an 80 year-old PWP who has stopped writing everything except his name, described his frustration with this impairment: "It burns me up sometimes that I know I'm scribbling and I can't straighten it out. [PD has] got me in the hands, and shaking like that." He went on to explain that this upsets him "because I can't do it" and elaborated,

When I can't do something, I get stressed out, whether [it's because] I've got Parkinson's or not. I'm just that kind of person. Like I said, you're working on something and it don't come out right [so] you're not going to be happy.

Another PWP with this symptom, 84 year-old Allen, explained that his inability to write prevents him from maintaining correspondence with some people in his social network:

Well, one of the biggest things [that PD has changed]—I like to write people notes and drop them a line, and I really can't do that anymore. My daughter got me—I tried an electric typewriter, and my tremor would set off the keys, so she got me a manual one, but I have about as much trouble with it, so I can't use it.

For Allen, as well as some other PWPs, not being able to write goes beyond being a mere inconvenience to causing the loss of a valued way of keeping in contact with others.

Having concerns regarding public self-presentation. Another salient challenge for PWPs reported by participants relates to having concerns regarding public self-presentation. Many participants discussed PWPs being embarrassed when signs of PD become apparent in public. Shaking, in particular, was frequently referred to as a symptom that PWPs often try to hide from others without success. Some PWPs, like Ray (who was diagnosed seven years ago at age 34), do not want anyone besides close family members and friends to know that they have PD, and are concerned that shaking will be an indicator of their illness to others. Ray's wife, Kelly, explained,

He still hasn't told most people. More people are starting to know, and he can't hide it. More people are starting to ask questions. Because his most prevalent symptom—everyday what you will see—is that he still does a lot of hand-holding, but he shakes a lot.

Ray explained his reasons for not disclosing the fact that he has PD, saying,

I just don't want it to get out. I don't think it's anything to do with the disease. I think it's me, myself. I just—I guess I don't want anybody to feel sorry for me or treat me different, so I don't say anything.

As previously mentioned, being treated differently because of PD can be a threat to a person's identity—and Ray tries to avoid this by attempting to manage his public self-presentation (e.g., holding his hands together to conceal his tremor). In some cases though, PWPs are so concerned about not being able to present themselves the way they want to in public that they opt to avoid social interaction. Paul explained that his wife, 71 year-old Sharon, went through a period (before having Deep Brain Stimulation surgery) in which she did not feel comfortable in public:

Oh, she was going downhill. I mean, she got to where she was always finding an excuse: “I just don't feel good and I can't go. Go ahead.” And I know she just didn't feel comfortable being around people because . . . they would see her shaking so much.

In sum, for many PWPs, concerns about self-presentation can be so troubling that they may either try to hide their symptoms from others, or even isolate themselves rather than deal with possibility of embarrassing symptoms manifesting in public.

In addition to broader concerns about people seeing them shake in general, PWPs may worry about coming across negatively (e.g., as incompetent or incapable) when participating in specific activities or performing certain tasks, including working, writing a check, engaging in physically-oriented hobbies, eating in public, and communicating. Lisa, a 47 year-old PWP, said that she worries about how others view her at work when her symptoms are evident:

Typing is probably the worst. The embarrassing part is I do work around clients a lot, and I've gotten to where I don't notice when I'm talking to a client, and I have my hand on the table, that the table's shaking.

Lisa wants to be seen as a confident, capable woman, and considers PD signs like shaking “very embarrassing” because they threaten the image she desires to project at work by making her seem, from her perspective, “nervous” or “abnormal.” Another PWP, 59 year-old Tina, also described concerns about being viewed as nervous—and, worse, dishonest—because of her tremor:

Something that happened to me a couple of years ago was I went to make a purchase somewhere, and I was writing a check, and I had to wait in line. These other people in front of me wrote checks. Then, [the cashier] asked me for three forms of identification for a check that was less than \$10. I think people mistake the tremor for, I’m nervous, and you know, I’m going to get caught or something.

Tina’s husband Ed, who was with her during this incident, also recalled it during his interview, saying,

There’s a big line, she’s digging out these IDs and you know, it really embarrassed her. So now, when she goes shopping, she’ll say [to me], “Do you have any cash on you?” That way, she doesn’t have to worry about writing a check, or she’ll write a check to the bank, go to the bank, cash it, and then have cash on her.

Tina was deeply embarrassed by the idea of being unjustly labeled by the cashier and those in line behind her as a possible “thief” (clearly, an identity inconsistent with how she views herself and wants others to perceive her)—and, therefore, she takes measures to avoid it happening again.

Many participants also reported being concerned about their public self-presentation when engaging in physical activities such as gardening. As previously mentioned, Ken, a 78 year-old PWP, recently gave up a cherished hobby—maintaining a garden plot at a local

college—because he fell on site a few times. In recalling these falls, he reacted to the fact that he had to receive assistance from a stranger each time because he could not stand up again on his own: “I’ve been stressed when I fall over and can’t get up. It’s a little embarrassing that somebody out there can’t even push himself up.” His comment is a poignant example of the emotion that can accompany a shift from being a physically fit, active, and independent person to someone who is not able to garden alone for fear of falling and not being able to stand back up.

Another physically-oriented hobby, engaging in sports, is also a source of concern for some PWPs in terms of self-presentation. Because sports typically occur in a public arena and require a certain level of physical aptitude, a loss of abilities can quickly become apparent (and be particularly identity-threatening). Kelly said that, despite the fact that her 41 year-old husband Ray has always been active in sports, PD has recently dramatically affected his abilities:

He loves sports. He is a very active man; he [was] big in softball especially, but now he cannot throw a softball. . . . He loved to play darts; he can’t throw darts [anymore]. And um, he had two different incidents—one with darts, one with softball—where he was trying to participate with other people, and he felt embarrassed because he couldn’t do it. That was when he realized what his limitation was on that. And that embarrassed him greatly.

The transformation from being active and capable in sports, to being unable to throw a softball or darts, is likely a significant threat to Ray’s identity. This challenge, Kelly said, is intensified by the fact that he is no longer able to practice sports with his teenage daughter: “The hardest thing, I am going to tell you, for that man right now is that our daughter is big in sports.” Another PWP, 63 year-old Greg, recounted a similar story about his embarrassment at his sudden

inability to throw a ball accurately, noting that this occurred as one of his earliest symptoms of PD (several years before his diagnosis):

I played softball a lot, all through my 20s, 30s, 40s, and would help with my kid's little league teams. I don't know exactly when this started, but . . . I suddenly—it seemed sudden to me—could not throw a ball accurately. It's like I couldn't really control my arm the way I was used to being able to, and it threw me for a loop. I thought, “What is going on?” . . . I would hang on to it too long, so the ball went down or I'd throw it over somebody's head, and it was really embarrassing for awhile. I was helping with my kid's team and sometimes I would be an umpire during the game, and one time, one summer, the umpires stood not behind the catcher, but to the side and back with the catcher. So the catcher would miss the ball, which is about nine out of ten times—[the kids were] 8, 9, 10 years old—the umpire would pick it up and throw it back. I was throwing it all over the place, and I was thinking, “What is going on?” It was so embarrassing.

For Greg, like Ray, suddenly becoming inept at throwing a ball was a dramatic shift from being a person who had participated capably in sports for the majority of his life. Besides resulting in the loss of an enjoyable pastime that each of these men previously shared with their child, not being able to competently engage in an activity that they had once participated in with ease caused them considerable embarrassment.

Participants also reported dining in public as a self-presentational challenge for many PWP. Some PWPs may avoid eating out, ask for a table that offers privacy from other diners, or order only “safe” foods (i.e., ones that are manageable to eat, even with a tremor). A partner, Carol, offered this example about how PD affects her husband Ken's selections at restaurants:

If we are out, he will order something that doesn't have to be cut. He loves steak but that's too bad, because [he] can't cut it and [he doesn't] want to be sitting in public not able to cut it.

Other participants similarly reported PWPs not ordering foods like peas or soup to avoid the embarrassment of spilling on themselves or others. Because being able to eat without spilling is an unspoken societal expectation of a "competent" adult, having difficulty with this task may threaten a PWP's identity and cause embarrassment.

Finally, PWPs' concerns regarding public self-presentation may also be related to communication. As discussed in a previous subsection, PWPs commonly experience communication-debilitating symptoms, including problems related to memory and concentration, the clarity and volume of their voice, nonverbal expressiveness, and writing. These issues can lead a PWP to feel self-conscious about how he or she is coming across to others. Ruth said that her 66 year-old husband Barry is embarrassed by "the fact that he can't remember somebody's name, the fact that he shakes, you know, and forgets what he is talking about. All those things." Moreover, Barry expressed a perception that these communication difficulties make him off-putting to "outsiders" (i.e., people he does not know well):

I just can't seem to communicate with outsiders too well. If they aren't able to carry on a conversation or something, I'm usually lost. I must not talk too clear or loud enough, because a lot of times, I notice they lose interest in my conversations or whatever.

As further addressed in the following subsection, this concern about self-presentation due to communication-debilitating symptoms also contributes to another psychosocial challenge: experiencing changes in sociability or social life. That is, because Barry has lost confidence in

his ability to communicate with people he does not know well, he has become less inclined to socialize.

Experiencing changes in sociability/social life. According to participants, PD can bring about changes in PWP's sociability or social life. Many participants reported that the PWP has become more socially withdrawn or introverted as a result of the disease. Although several PWPs mentioned this change, it was more frequently cited by partners as a challenge experienced by PWPs. Moreover, partners often noted that they were unsure about exact cause of this withdrawal (e.g., fatigue, depression); however, it seems clear that, in many cases, this reduced sociability stems at least in part from the PWP having communication-debilitating symptoms. In the example given in the previous subsection regarding Barry's trouble in talking to "outsiders" because of his problems with memory, difficulty communicating has made him concerned about public self-presentation, which, in turn, has resulted in him being less inclined to socialize with people who he does not know well. Another PWP, 78 year-old Ken, also said that he no longer talks as much as he used to at social gatherings, not only to avoid the embarrassment that can accompany his communication difficulties, but also because communication has simply become so much more effortful for him:

In the [social clubs], they're sometimes asking for me to say again what I just said, because it wasn't loud enough or it couldn't be understood. It's caused me to be kind of quiet; I don't participate in conversations as much as I used to. I start a sentence and I know exactly what I want to say, but I come to a point and I can't think of that word, fumble around and finally get a substitute and go on, which is not as good. . . . It's hard work. It's a bit embarrassing and it's a lot of work now.

For some PWPs, like Ken, it is easier to stay quiet in certain social situations than to work hard at trying to maintain a conversation and risk becoming embarrassed due to communication-debilitating symptoms.

Other changes in social life can occur as a result of no longer being able to participate in a social activity due to PD. Calvin said that his partner Wanda, a 71 year-old PWP, has lost touch with some of her friends after dropping out of a bridge group (because her tremor made it difficult to play). He recalled, “They drifted off because she had been in a bridge club that met monthly for years, a group of ladies.” Laura, a 67 year-old PWP, explained that she now declines most invitations because of the difficulties she associates with attending social events (particularly without her husband):

It [is] just almost better to curl up in the recliner with my jammies on than to have to get ready and go and all the hustle and bustle. If I could just know for sure that I wouldn’t have a problem but, you never know, well, how things are set up—like if I’m invited to a shower at someone’s home. I’m just not sure I could handle it.

She went on to list concerns related to getting around at someone else’s home with her walker or in her wheelchair, possible difficulty getting up and down (e.g., to go to the bathroom) without her husband’s help if he has not been invited as well, and not knowing whether her medication will wear off more quickly than usual due to excitement.

Being unable to predict daily well-being. The experience of having PD can also be difficult for PWPs because of the unpredictability of how they will feel each day. Deb, a 73 year-old PWP, conveyed the attitude that she has learned to have in response to the sometimes volatile trajectory of PD:

Enjoy everyday, and whatever you can do, just do it, because you never know what the next day's going to be. That's the worst part of it. It's kind of a blessing in disguise because some days aren't too bad. Some days are pretty good. You just don't know.

Although she tries to remain positive in coping with this chronic uncertainty, Deb expressed frustration at how difficult it has become for her to make plans: “[Friends] call me: ‘When you feel like doing something?’ Well, because if I make plans, when the day comes, I may or may not be able to do it, because no two days are the same.” Another PWP, 69 year-old Anna, also said that the unpredictability of the disease sometimes forces her to cancel prior commitments:

Well, I have mostly good days, but if I go on a roll, like I had three or four good days, I'm going to crash. So I get out of—I can get out of most of my situations that I needed to face up that day. I can pretty much get out of them. I volunteer at [name omitted] and a few times, maybe three times a year, I've had to call and tell them—they know I have Parkinson's—I just call them and tell them that I don't feel good enough to come in. I just take it easy that day.

Anna went on to say that living with chronic uncertainty has required that she recognize and accept that she may not always have productive days. She explained, “I am used to getting lots of things done. So now, I just say, ‘You're not going to get lots of things done today.’ First, it was a shock that that would happen, but now I'm used to it.”

Feeling uncertain about disease progression and the future. Finally, in addition to unpredictability regarding daily well-being, PD can also bring uncertainty related to longer-term disease progression and the future. Due to its variable (though progressive) trajectory, many PWPs expressed uncertainty about how quickly their PD would advance. A partner, Joe,

summarized his 47 year-old wife Lisa's "biggest thing that scares her" since being diagnosed with PD less than a year ago:

She wonders what she's going to be like in ten years. We're looking at retiring in ten to fifteen years. She still wants to be able to run around with our grandkids, and she's afraid she won't be able to.

For some PWP, like Lisa, not being able to envision what their health will be like in the future is a salient source of uncertainty. Several PWP mentioned going beyond just thinking generally about disease progression, to wondering if or how PD actually leads to death. Cheryl, a 76 year-old PWP, said,

I'm just curious on how—what the Parkinson's does to kill you. I don't know if it's like MS [multiple sclerosis] that you—all your muscles stop, including your heart. I don't know. I don't know. I'm just—I guess it's interesting. It seems silly.

Cheryl reported regularly reading the newspaper obituaries and becoming very curious by those that reported deaths with PD listed as the cause, as did another PWP, 70 year-old Carl. Carl explained his uncertainty:

I haven't gotten a straight answer out of any of the authorities on what the course of this disease is. People who should know say you don't die from Parkinson's, but you see obituaries all the time that say the person died from Parkinson's. Friends that I had who died from Parkinson's died from falling down, breaking their pelvis, going in a nursing home, getting an infection and dying and they fell down because of Parkinson's, but they didn't die [directly] because of it.

It is difficult to know whether Cheryl and Carl, and other PWP asking questions about if or how PD causes death, are genuinely interested in reducing their uncertainty about this issue.

Conversely, they may (perhaps even at a sub-conscious level) be hoping to maintain their uncertainty about upsetting information, or to find comforting information (e.g., that PD does not typically lead to death) as a means of emotional protection.

PWPs also reported uncertainty about their future care. Laura, age 67, wondered what would happen to her if her husband Howard was not able to continue caring for her:

Well, the thing that I have thought about is: Of course he's my caregiver, and if something would happen to him, I'm going to a nursing home. That's my only fear, and it shouldn't be that way because I'm being kind of selfish, but that is a concern to me. Well, I wouldn't expect anybody [else] to take care of me, but I wouldn't want to go to a nursing home either.

Similarly, 73 year-old PWP Deb expressed concern about going to a nursing home if her PD becomes so advanced that her husband Larry cannot care for her:

My mother-in-law is in the nursing home. It's very difficult to go out there because I keep thinking, "Am I going to be out here before long?" We've been to a few meetings of the Parkinson's support group where the husband went to the nursing home and picked up his wife and brought her to the support group meeting, and I thought, "Oh, damn, you know, that wouldn't be too good."

Having uncertainty about future care can be fear-inducing for some PWPs, like Laura and Deb, who are upset by the possibility of living in a nursing facility at some point down the line.

Psychosocial Challenges Experienced by Partners

Partners are likely to encounter a multitude of challenges as a result of their PWP having the disease. Specifically, participants detailed psychosocial challenges experienced by the partner related to (a) being unable to "rescue" the PWP from the challenges of PD, (b) being the

recipient of the PWP's frustration, (c) getting impatient with the PWP, (d) shouldering increased responsibility, (e) missing the PWP's pre-PD identity, (f) being confronted with the prospect of losing the PWP, (g) losing valued activities, (h) having the PWP withdraw from communication, (i) feeling housebound due to the PWP's dependence, (j) being unable to predict the PWP's daily well-being, and (k) experiencing uncertainty about future caregiving and disease progression.

Being unable to "rescue" the PWP from challenges of PD. Many partners reported not being able to "rescue" their PWP from the difficulties of PD as a salient challenge. In explaining the hardships experienced by the PWP, partners often became emotional—expressing sadness, frustration, and concern at not being able to ease the burden for their loved one. Denise, whose husband Greg was diagnosed four years ago at age 59, described how Greg has begun working incredibly long hours at his job in order to compensate for his reduced ability to concentrate:

I think he's frustrated. . . . The Parkinson's he feels like is really slowing him down, his concentration. I don't know how he does it. I would be so mad at the world because he works—I mean, it's no exaggeration. He has adjusted his schedule because he feels like he works better at night. He'll come home from work at 6:30, [then] he'll work from maybe 8:00 to midnight, go to bed for some hours . . . and then he'll get up at 8:30 and work straight through until 6:30 again. Seven days a week.

She went on to say that Greg maintains this grueling schedule because he feels he has no other option:

I know he's concerned about keeping his job. He feels like Parkinson's is a big factor in that, and unfortunately, with the economy and the financial losses with the economy, neither one of us—retirement is not in the near future. It is what it is, but it's not like he's

thinking, “Oh, two more [years]”—you know, he's not thinking 65. We're both probably going to collapse at our desks.

Knowing that they need to maintain their status as a dual-income couple, yet wondering about the health ramifications of Greg working so much, leaves Denise feeling helpless and worried for her husband. She explained,

I get so concerned about the amount of stress and work he is involved in, if that's keeping him going or if that's hurting, causing distress. I guess somehow wishing I could make it better. I feel so horrible that he works so hard and with such a good attitude. I don't know how to make it any better for him. . . . He's not trying to get ahead. He's just trying to keep up.

For many partners, like Denise, desperately wanting to help the PWP and not knowing how to is a major stressor.

In some cases, this inability to eliminate the PWP's struggles can threaten partners' own identities (e.g., as a “fixer,” “protector,” or “rescuer”). Kelly, whose husband Ray was diagnosed with PD seven years ago when he was in his early thirties, explained,

I don't know . . . I think [my biggest challenge] is that you can't fix it; that's the hardest part. . . . I've gotten angry with him once or twice, and I am like, “You know what, you are not the only one doing this. Quit acting like it's all you.” My mom thinks I am a terrible person for that. Um, but like I told him, “You are not the only one that's going through this, your kids are dealing with it, I am dealing with it. . . . You think it's fun to sit back and know there is not a dang thing I can do to fix this? I am a fixer, I am a mother, I do everything, I fix everything, I make it all better.”

For participants like Kelly, not being able to protect the PWP from PD is especially frustrating because “mak[ing] it all better” for loved ones is such a deeply-embedded part of who they are.

Being the recipient of the PWP’s frustration. Another challenge discussed by some partners was the fact that their PWP sometimes seems to become aggravated because of a symptom of PD, but then takes out that frustration on them. Ruth described how her husband Barry’s earliest symptoms of PD were related to his memory: “You know, he would forget different things: ‘Where’s my keys?’ And would be going someplace driving and would say, ‘How do I get there?’ And just little things like that, you know.” She went on to explain that, over time, 66 year-old Barry has become more irritated by his PD-induced memory lapses and occasionally directs that annoyance towards her:

He gets frustrated sometimes and he takes it out on me. Which, it just rolls of your back because it doesn’t do any good to fight about it. As far as that goes, you know. And that’s not an everyday occurrence, you know, it’s just the fact that he needs something and he forgets where he put it—those kinds of issues. “Well you had it last, so where did you put it?”

Another partner, Ed, described a similar phenomenon regarding his wife Tina, in that Tina sometimes acts upset with him when he suspects it is actually misguided anger stemming from her being frustrated with having PD. Of 59 year-old Tina, who reported becoming increasingly creative but less able to concentrate on tasks because of dopamine changes related to PD, Ed said,

She does get frustrated a lot because she’ll be into something—it’s almost like she’s developed ADHD [Attention Deficit Hyperactivity Disorder]. She gets off track, and when she gets done with something, she sits it down and doesn’t put it away. I go around

picking it up and putting it away, and then later on she'll say, "What was I doing?" and then she'll get all the stuff back out again. Then she gets mad at me and I just—okay, whatever. Be mad for a while. Usually, I just try to take it one day at a time.

Getting impatient with the PWP. According to many participants, just as PWPs sometimes take out PD-related frustration on their partners, the opposite occurs as well. Partners discussed having difficulty maintaining their patience with their PWP at times for issues related to PD (or the caregiving necessitated by the disease). Several participants noted that losing their patience with their PWP often has less to do with the other's behavior than it does with their own emotional state. Doug described a dark period he went through after his 69 year-old wife Anna was diagnosed four years ago:

I got very negative, and I got to be really hard to be with her, impatient with her, kind of like in a caregiving relationship. The caregiver—one of the challenges, no matter what, is an impatience with the person because you yourself are emotionally stressed. So then you become impatient and negative. That kind of thing.

Doug explained that he was depressed about the ailing health of his wife of 25 years, and knew that he needed help in managing not only his own distress but his lack of patience with Anna when she needed assistance due to PD. He continued, "So I finally just went to my doctor, and he referred me to a psychologist. For a year, I took some antidepressant medicine, which was quite effective, I must say."

In addition, several partners mentioned the notion of emotional contagion, saying that it was important to have patience with their PWP because their moods affected one another. Martha, who spends the majority of each day at the nursing home where her 72 year-old husband Donald resides, provided this advice to other partners caring for PWPs:

Always use a gentle tone of voice, but that is personality, too. Donald's easily hurt, and if I am frustrated and use an anxious tone of voice, he can pick up on it right away. You're always a gentle, loving voice.

When asked by the interviewer, "How does he react? What does he do if he can tell that you're frustrated?" Martha went on to explain,

He bristles, and then he gets angry. His mood seems to follow my mood. It's difficult, 'cause there are days your back hurts, your foot hurts, you're tired, you woke up with a headache, but you can't let it show. I think the most important [advice] is take your time. Don't rush, even with eating. It takes me an hour to feed him now. Don't rush.

Other participants echoed Martha's sentiment about the importance of not rushing—and in particular, not telling their PWP to rush. Because one of the primary symptoms of PD is general slowness and stiffness in movement, PWPs may take an extended amount of time to complete tasks that used to be effortless. Some partners reported feeling guilty about sometimes becoming impatient with their PWP during such tasks. Judith, whose 89 year-old husband Lawrence has considerable difficulty with such movements as getting out a chair and walking, said, "Sometimes I tell him to hurry, and I never, never should do that. He can't hurry."

Similarly, another partner, Howard, commented on his goal of being more patient in terms of the "freezing" that his 67 year-old wife Laura periodically experiences in her lower extremities. Because of this debilitating symptom (which results in a temporary inability to move her legs and feet), Laura, who has had PD for twenty-six years, typically uses a walker or wheelchair so as to not lose her balance and fall. Howard said, "Sometimes I'm not patient enough with her pace." Finally, Carol, whose 78 year-old husband Ken remains active but moves slowly due to faltering balance, recalled,

Sometimes I do [whatever I've asked him to do] myself, and I know at the time I shouldn't jump in this quickly and do it and I'll say something like, "I can do that, just let me do that," because I am frustrated. Frustration, I suppose, [because] you just think, "Oh I have got to get this done," and sometimes, it's interesting—I have thought about that recently, kind of dwelling on it, but I think I get mad about it sometimes, at him, and then I realize it's not him, it's the Parkinson's. I told him that recently, "You know I can be grouchy and I can get crabby, just because you can't do this, you can't do that." I told him, "I realize I am not mad at you, I am mad at the Parkinson's."

For Carol, mentally separating the disease from the person helps her maintain her composure with her PWP and avoid losing her patience.

Shouldering increased responsibility. A majority of partners reported taking on increased responsibility as a challenging aspect of PD. These additional roles and duties ranged widely. Several partners, for example, discussed being the sole financial provider as a very stressful consequence of their PWP having PD. Pam, a 51 year-old partner, explained that her 47 year-old husband Jack had been laid off from work some time before he was diagnosed with PD less than a year ago. Because of his declining health, the possibility of him ever returning to work had become unlikely and, with it, so had reaching her goal of retiring some day:

Right now, I'm the provider, and I guess I always thought that there would be a change in that, and now that's a reality that I'm facing again: That hope [of retirement] that was kind of out there is not even a window anymore. That's a nice painted wall. [Laughs] I've had to deal with those emotions, not be resentful. It's like this is where we're at and facing that. . . . I don't want to say the word "trapped," but some days, it's like that trapped feeling of, what are you going to do?

Other partners listed such tasks as cleaning the house or managing the finances as responsibilities that they had taken over because their PWP had begun struggling to do them.

Ruth explained that, as a partner of a PWP who has trouble with balance,

you pick up a lot of extra things. . . . And even just little things, changing the batteries in a smoke alarm, which went off at 2 o'clock in the morning the other night. Every ten minutes, beep beep. We never had an alarm where the battery lets you know it's going dead in the daytime. [Laughs]

Many participants noted that the burden of these additional tasks can take a toll on partners.

Anna, a 69 year-old PWP whose husband Doug had taken on more cooking, cleaning, and driving since her diagnosis four years ago, noted,

I think he doesn't feel as free, and [the responsibility] is kind of overwhelming for him. I mean, I think it's harder for him than it is for me right now. I said something about, "thank you" or something, and he said [sarcastically], "Oh, I said 'til death do us part."

Furthermore, some partners felt that the diagnosis of PD had led to added pressure for them not only in terms of looking out for their PWP, but also other family members. Jack's partner Pam said,

I think the spouse, whether it's the wife or the husband, in this case, the wife, feels like okay, I've got to stay healthy. I've got three kids to tend to. And then he'll come back with a comment: "I'm not dead." Yeah, I know, but I guess that's where it's changed. I don't want to put any more burden on him or make him feel stressed. When the stress level rises, the symptoms really peak, or you can see them more and hear it in his voice and in his walking.

For partners like Pam, the pressure to try to independently handle family responsibilities is motivated by a desire to protect the PWP's health. Finally, Kelly, partner to Ray (who was diagnosed with PD in his thirties), described the experience of worrying about not only him and their kids (aged 13 and 16), but also their aging parents.

You know, I got too many people depending on me, I got the two kids, I got, I mean his parents are much older than my parents even, and his father is already legally blind. His mother has heart problems. I mean they are very well; they take care of themselves very well. But Mom is the only one that can drive, and she has difficulty. She had difficulty with her eyes here not too long ago. We were afraid that if we didn't get something done she was going to lose her driving privileges. And then I am like, "Oh my gosh, what are we going to do?"

Kelly summed up the overwhelming sense of increased responsibility she has felt since Ray's diagnosis seven years ago: "It's all on me now."

Missing the PWP's pre-PD identity. As described in the subsection about challenges experienced by PWPs, the manifestations of PD can be highly threatening to the identities of people with the disease. In some cases, participants commented on the fact that these changes in a PWP's identity affected the partner as well. In speaking about the ways her interests and priorities had changed since being diagnosed with PD seven years ago at age 52, Tina said, of her husband Ed:

Occasionally, he's told me that he misses me. He misses the—I used to be a gourmet cook, and I spent a lot of time doing it. Now I could care less. Feed me a hot dog and I'm fine. So he misses that, that bread-making wife. She just doesn't care at all anymore.

Glimpses of the PWP's pre-PD identity may incite an emotional reaction from partners because they serve as reminders of a time before illness. In discussing the ways his wife Pam had been impacted by him being diagnosed with PD in his forties, Jack said:

I know she's had her times. I do recall now that there was one time. . . . It was Easter.

That's when it was. We had a family gathering, and I'm often asked to say the blessing for the meal, and so I prayed, and I prayed in my pastoral voice, and Pam disappeared after we said grace and started to form a line to eat. So I went looking for her, and I found her, and she had broken down. She said, "That's the old you, the you that I know." That's the most emotional I've seen her.

Pam described him, and Jack described himself, as a highly religious man who gets great satisfaction out of communicating his love for God publicly as well as privately. Hearing Jack publicly pray in his "pastoral voice" (which he described as strong and deep) invoked strong emotions in his wife, likely because it represented a treasured part of his identity—and a part that had been threatened by PD, in that his voice had become softer and less clear in the months since he had been diagnosed.

Being confronted with the prospect of losing the PWP. Partners may also face the challenge of confronting the possibility of their PWP dying from PD. Many participants mentioned being comforted by the fact that PD does not typically pose a threat to life until the advanced stages (when potentially fatal complications can occur); however, several PWPs and partners recalled being initially terrified by the diagnosis and wondering if death could be imminent. Doug, a 64 year-old partner who began suffering from depression immediately following his wife Anna's PD diagnosis four years ago, explained the reasons for his depression:

[It was a result of] changing our roles and our relationship, but then being confronted with her health as a fact of possibly losing her. So it's like you're grieving. You enter into grief, because you don't know. And yet it's serious enough that you don't know that this may be something that's the end. And then there's a grieving with that. So you face that sort of thing.

Whereas Doug's depression in response to facing Anna's mortality subsided as they came to terms with the diagnosis and learned more about the disease, other participants reported a different trajectory: increasing sadness about the prospect of losing the PWP as the disease progresses. Helen, an 80 year-old partner, fought back tears as she described the thought of losing her husband of sixty years as her biggest challenge related to him having PD:

I just feel like crying. You get the blues. Sometimes, you get kind of depressed. You think [to yourself], "Well, what do you expect? Look how old you are. You're lucky you had him this long." I looked at the paperwork and thought gosh, [the diagnosis] was 2002. We've been lucky, really, when you look at it that way. But when you're married so long, you can't imagine not having each other. That part's hard.

Another partner, Martha, spoke poignantly about believing that her husband of forty-six years, 72 year-old Donald, would be "going home to God" at some point soon. Although she expressed comfort at the peace she felt death would bring him when it was time, she also shared her grief: "What I'm feeling inside is just overwhelming sadness."

Losing valued activities. Symptoms of PD often hinder the PWP's ability to continue leisure activities and, when those activities are shared (as they commonly are among members of a long-term couple), being forced to discontinue them can represent a loss for the partner, too. In some cases, this sense of loss for the partner goes beyond not being able to engage in a joint

activity with the PWP. That is, some partners reported experiencing the discontinuation of activities due to PD as a personal (i.e., individual) loss (in addition to a communal one shared by the PWP). For example, Helen, who at age 80 has enthusiastically enjoyed dancing for most of her life, expressed sadness at losing this form of recreation. Although she and her husband Walt still go to dances occasionally, they now sit on the sidelines because his PD does not allow him to move freely enough to dance. She explained,

I miss it. When we go to the dances, that's hard, too, because he does not like me dancing with other people. That makes it hard, and I love to dance, and it's not that I like these guys, but if they ask me, I'll [want to] go yeah, but [then] I look at him. . . . It's hard because, if he's not dancing, I'm not dancing. . . I guess you could say his losses become my losses.

Another way in which partners experience losses in valued activities due to PD is as a result of their PWP's inability to travel. While this is often experienced as a communal loss, it can also feel like a personal loss for partners (as well as PWPs) at the individual level, as illuminated by 57 year-old partner Ed:

I've lost my dreams. She can't travel. I always thought whenever she'd be retired we could get a small motor home and just go places, a lot more places, and things like that. . . I thought we'd travel, see the United States. That's not going to happen now.

Similarly, Larry who, at 73, is recently retired, spoke of not being able to travel as a loss that had resulted from his wife Deb's PD: "I've always had a wandering spirit and I guess—I guess I always imagined I'd be traveling the world or something at this point in my life."

Having the PWP withdraw from communication. Some partners mentioned that they have begun to feel emotionally distant from their PWP as a result of the fact that the disease has made

the PWP “turn inward” and become less interactive. Of her husband Walt’s increasing introversion, Helen said,

I get lonesome. But for me, I don’t think he notices. For me, it’s like he’s there but he’s not there. It’s me talking all the time. I ask him a question, like I found a magazine: “Do you want me to keep this or not?” Yes, then he’ll answer. But once in a while, he’ll surprise me. He’ll ask me a few questions, like about the birds that were in the trees: Did I see all that?

Helen described this mostly waning, yet vacillating, engagement in conversation as perplexing. She explained that, although Walt (who, at age 80, has had PD for eight years) has started to show some signs of memory loss,

It’s not like he’s in a fog. It could be he’s just bored, and to me, that’s hard, because I can’t think of anything for him to do. I don’t know if he’s not listening, but I’ll say to him sometimes if he’s just sitting, “What are you thinking?” He can’t tell you what he’s thinking, or he doesn’t want to tell you what he’s thinking. I don’t know that.

Another partner, Edna, expressed similar bewilderment about her husband Eugene’s diminished interaction with her. Diagnosed ten years ago, 73 year-old Eugene has become progressively withdrawn, as Edna explained:

He’s never been much of a talker, but he’s more quiet. He can sit for an hour or two hours and just stare off into space. I’ll say, “What are you thinking about?” “Nothing.” I don’t know. So whether he’s just not wanting to communicate with me or if he really is just in a vacuum, I don’t know.

In addition to feeling confused and concerned for the PWP, the partner may feel upset at being closed off from her or his primary conversational partner. Martha explained that her 72 year-old

husband Donald has become increasingly quiet as his PD has progressed in the four years since diagnosis and, as a result, her own desire to communicate is often unfulfilled. She said, “With Parkinson's, you don't talk as much or you start to have communication problems. I'm an extrovert. I need to talk. That has been frustrating.”

Feeling housebound due to the PWP's dependence. A challenge that tended to be reported by partners of PWPs who had advanced cases of PD was that of feeling housebound because of concern about leaving their PWP home without them. Several partners said that they prefer not to leave their PWP alone for more than a short period of time due to fear that the PWP might need care or experience an emergency (e.g., falling). Edna, whose 73 year-old husband Eugene struggles with balance and becomes anxious upon her going anywhere without him, explained that, although she does not feel comfortable leaving him, taking him with her to run errands can be difficult as well:

[Sometimes] I take him with me. In the grocery store, when I'm trying to get groceries: “Come on, let's go home.” He repeats it constantly. If I'm going to Wal-Mart, he'll go in there, but if I'm going to any of these other stores, he'll just sit in the car. But now when it gets [to be] cold weather, I'm going to have to leave him here at home, and I can leave him for like an hour, hour and a half, because he'll usually lay down and take a nap, so I feel safe doing that, but I don't feel safe after that length of time. I feel like I need to just grab what I need and get back.

Helen, whose 80 year-old husband Walt becomes too fatigued by walking to accompany her on most errands, expressed a similar sentiment, saying, “I don't like to leave him. That's the hard part. Well, if I want to go somewhere an hour is probably my limit. If I go over an hour, then I

get kind of worried.” She went on to describe safety checks she had in place for those occasions that she felt she had to leave Walt:

If I really want to go for longer than an hour, maybe two hours or something, my daughter lives a couple of blocks away, so I'll call her and say, “I'm going.” We just did this maybe twice. “Check on Dad.” [But] if she calls on the phone, it takes too long for him to get out of the chair to get to the phone. And the problem is, he can't use a cell phone, so—I don't like to leave him for any period of time, but he does have—we have this [emergency] phone, which is through Nationwide, and he wears a bracelet so that—the trouble is [whether or not] he would push it. So if he would fall and he can't get me, he could push the button and then it rings there and then they call the kids or somebody comes.

It was clear that, despite her efforts at providing safeguards, Helen was not at ease when Walt was home alone; she reported constantly worrying about him when she was away from him and leaving their home for only the shortest periods possible.

A consequence of partners not wanting to leave their PWP alone can be social isolation. In describing the challenge of not wanting to leave her 89 year-old husband Lawrence at home alone out of fear that he might choke while she was gone (due to a swallowing problem related to PD), Judith said, “I feel homebound. Yeah. I don't get away as much as I used to. I miss that.” She continued, saying that she tries to make time for the occasional meeting with friends, but admitted that the situation could be challenging:

We've got a new tearoom in our little town, so I sometimes meet my friends there for an hour or two, and that works, as long as he's got the phone. I was a hospice volunteer for a number of years, so I've kind of been able to understand things like this. Whoever thinks

of what your life will end up? I didn't. I'm here now, and that's where I am and we go on with that.

Being unable to predict the PWP's daily well-being. According to many participants, being the partner of a PWP entails the significant challenge of not knowing what each day will bring in terms of the PWP's health. Calling PD a “moving target” because of its unpredictability, Doug described his 69 year-old wife Anna's health in this way:

From my point of view, the difficulty is not knowing how she's going to be. . . . You're going along and things are well, let's say. You're like, “Everything's fine and we're okay.” And then all of a sudden she's not well, and you go, “What happened?” And then that can become depressing. Sometimes, she may be okay for a week and then not be so good for three days, and there's no way to know. Or there's no way to know on a given day sometimes, whether she may start out and feel really bad and get better.

He explained that this volatile trajectory has been very stressful for him because of the interdependence he shares with Anna:

I had a difficult period with that—adapting to the varied ability of how—of daily living, not knowing whether it's a good day or a bad day and having to deal with that, both literally in terms of planning and emotionally in terms of—you feel better when your partner's feeling good. You're better. When your partner's not feeling well, it's not as good.

Other partners discussed this daily uncertainty about their partner's well-being in terms of fearing that the symptoms of PD might lead, at any time, to a catastrophic event. Ruth, a 64 year-old partner who works full-time in order to maintain health insurance for herself and her husband Barry, described worrying about Barry's safety on a constant basis:

He is alone most of the time, because I leave for work at 6 in the morning usually, or 6:30. And I never know when I get home, is he going to be laying some place, or has he fallen during the day? Which has happened a couple of other times. . . . Oh yeah, I worry if he tries to cook, with the memory, is he going to leave the stove on? Just routine things like that.

Ruth's concern about her PWP falling was echoed by many partners, including Joe. Since his 47 year-old wife Lisa was diagnosed with PD less than a year ago, he has been in a continuous state of watching and worrying. He explained, "I kind of really have to watch what she's doing because she could easily fall and knock herself out and if nobody's there, she can lay there for a long time." Finally, some partners reported worrying about other types of PD-related emergencies, such as their PWP choking or getting pneumonia due to an inability to swallow normally. For Judith, this possibility is a source of daily stress and one that she has talked to her 89 year-old husband Lawrence about. She said that although he physically struggles with swallowing,

He knows how to swallow and what happens when you don't swallow and the little things like you're not supposed to use a straw to drink. Again, the therapists have explained that to him, but that's the thing that concerns me is the cough. If it will go the wrong way, then it's going to lead to pneumonia.

For Judith and other partners, continuously worrying about the PWP's daily well-being can result in a state of chronic uncertainty.

Experiencing uncertainty about future caregiving and disease progression. In addition to day-to-day uncertainty, partners often cited longer-term uncertainty related to PD as a challenge. Clearly, having uncertainty about the future, like many other challenges, is an issue shared by

PWPs and partners; however, partners frequently mentioned that they anticipated being in the unique position of being the one to make decisions about the PWP's care in the years to come. Many partners discussed being vehemently against moving their PWP to a nursing home. Carol, whose 78 year-old husband Ken does not yet require enough care for her to consider herself his "caregiver," pondered the future:

I suppose if it progressed to a different stage then you would think of yourself that way. One thing that I have always thought is I wouldn't want him going to a nursing home; I will do everything I can to keep both of us at home. Everybody says, "Aren't you doing something about that two-story house?" I am starting to clean and maybe move to a one-story house; we are thinking about it. I would do anything to keep us—of course my folks were in a nursing home. . . . And you lose a lot; I know my mother lost a lot when she went to a facility like that. And I could see that happening, so I would not want that. I would hire help or whatever I needed, but that would be a goal, to stay at home.

Other partners had questions about how quickly the disease would progress in the future, and what that progression would eventually entail. Teresa, whose 67 year-old husband Warren was diagnosed with PD about a year ago, wondered, "What will he be like in 10, 15 years? Will I be picking him up off the floor?" Joe's uncertainty about what his 47 year-old wife's eventual progression would be like scared him because it brought to mind an image of a deceased loved one of his:

The biggest fear is if the Parkinson's progresses to the point of paralysis, because it does. It can happen. I don't want to see that happen to her. My grandmother had [Alzheimer's and Parkinson's], and it was just devastating to go to the nursing home and see her curled up in a ball, and I don't want my wife to go through that.

Relational Issues

In addition to challenges that primarily pertain to either the PWP or the partner as individuals, the experience of PD often brings a host of related issues regarding the couple's relationship. Participants described relational issues stemming from PD in regards to (a) experiencing changes in overall relational closeness, (b) shifting relational roles, (c) experiencing changes in sexual intimacy, (d) facing financial stress, (e) engaging in fewer leisure and social activities together, and (f) experiencing uncertainty about their relationship.

Experiencing changes in overall relational closeness. When asked whether PD has changed the overall level of closeness in their relationship, the majority of participants said either that there has been no change or that it has made them closer; however, other participants said that they have become less close because of PD, or that they experienced a past period of decreased closeness due to the challenges of PD but have worked through it. Among those who said there has been no change, many participants cited their long and stable history with their partner as the reason that PD has not affected their relational closeness. In speaking about his marriage, Ron, a 68 year-old PWP, said, "No, [our closeness] hasn't changed. We've known each other for a long time. We've been married 44 years. We dated in high school and actually go back to [name omitted] nursery school. Our relationship is pretty solid." His wife, Bonnie, echoed this sentiment: "When you've been married as long as we have, it takes a lot to shake things up." Other participants, like Greg, said that having PD has not affected their relationship in any facet, including closeness, but acknowledged that relational changes could occur in the future with the progression of the disease. Of his relationship with Denise, his wife of 30 years, Greg said,

My first thought is I don't see that [PD has] really changed anything now. We both know I've got Parkinson's . . . but she can see as well as—maybe better than—a lot of people that it's not affecting me to a great extent. To that extent, it's not—it hasn't been a huge factor in our relationship. I'm sure if and when symptoms get worse, it will become more of a factor and she'll feel like she maybe needs to help me in some ways, but as I mentioned earlier, I'm hoping and praying that maybe I'll die from something else before the Parkinson's screws things up and becomes a major factor.

Some participants indicated that coping with the challenges of the disease has made them feel closer to their partner. Lisa, a 47 year-old PWP whose illness has progressed rapidly in the six months since her diagnosis, described changes in her relationship with Joe, her husband of 20 years: “I would say [since my diagnosis] it’s gotten even better. He’s just been great with everything. It doesn’t affect our sex life in any way. He does the dishes, he cooks, he cleans.” In his interview, Joe responded similarly when asked whether the closeness between he and Lisa has been affected by PD, saying, “I’d say we’re actually closer.” He explained,

I’m more involved with her daily activities. . . . Yeah, there’s more collusion there. We work together and do stuff now. . . . It’s spooky sometimes: She’ll finish my sentences before I even start one. We’ve just never been happier. It’s a lot more work on my part, and she knows it.

Other couples also highlighted support provision from the partner to the PWP as a catalyst in making both members of the couple feel closer to one another. Walt, an 80 year-old PWP, expressed gratitude that Helen, his wife of 60 years, takes care of him, saying, “It kind of brings you closer together because she’s helping me out a lot.” Ruth explained how taking care of her husband Barry, a 66 year-old PWP, has changed their marriage of 46 years: “I think we

are probably closer. It's a protective instinct in me. So to make sure he has good food and this and that." Another partner, Martha, also said that her relationship with her 72 year-old husband Donald has "gotten better" as a result of her taking on a protective role over him since his PD diagnosis nearly four years ago. Although Donald now resides full-time in a nursing facility without Martha, she typically spends over twelve hours a day with him there, providing extensive hands-on care, including feeding, dressing and toileting. She reflected on their 46-year marriage and their recent increased closeness:

He's my focal point now, where before, the four kids were my focal point, along with taking care of my family—Mom, Grandpa, Grandma, and Aunt—and then going into the business. That was my focal point, and he had his. He did his thing. Early on in our marriage—I'm a very busy person, and he got real frustrated with me one time, and he said, "I really don't want to go [to your events]. Tell you what: You do whatever you want to do. Just don't ask me to do it with you." That's just kind of the way we lived. Now, he's my focal point. He loves it. Our relationship has gotten better; we're closer. I think I'm going to miss that when the end comes.

For some couples, like Martha and Donald, coping with PD can lead to enhanced relational closeness by prompting a shift in how much attention is focused on one another.

Compared to participants who described either experiencing no changes in closeness or becoming closer as a result of PD, fewer participants said that they are currently less close with their relational partner, or that they experienced a past period of decreased closeness, due to PD. In some cases, not being able to participate in leisure activities together can result in diminished closeness, as stated by partner Edna, whose husband of 29 years, 73 year-old Eugene, has become mostly housebound because of PD: "Well, I guess maybe we're less close because we

can't do everything together. We always did everything together, and now we can't." In a few other cases—like couple Tina and Ed, married for 22 years—participants described PD as making the PWP feel less secure and, as a result, less close, in their relationship. Ed explained,

She has a little problem thinking that [because] she's got Parkinson's, I don't want to be around her. I tell her, "Bullshit. If I didn't want to be around you—when I come home every night—if I get off work at 5:00, I'm home by 5:05. I could always say, 'Oh, I'm stressed out. I need to go have a beer.' I don't. I come home."

Tina discussed feeling less close to Ed since her PD diagnosis seven years ago, saying that, now more than ever, she needs support beyond just his physical presence: "I do feel less close. Sometimes, I'm more lonely now when he's there than when he's not. It's kind of an odd thing. If he comes home and he turns on the football game immediately or whatever, I'm just as lonely [as when he wasn't home]."

Finally, several couples recalled going through a period of decreased relational closeness as a result of the challenges of PD, but said that they had worked through this. Kelly described a very difficult time in her marriage that resulted from her 41 year-old husband Ray being unwilling to discuss his PD with her:

He just wouldn't talk to me about it so we grew apart, and we fought, and we got very—I really seriously thought we were getting a divorce about two years ago. That's how bad it was. And um, I'd say the last couple years we've worked really hard, and the last year especially things have gone very well. We're still not, we'll never be a perfect couple. . . . You're never a perfect couple, but um, things are much, much better than where they were. We actually talk, we're actually interacting again.

Kelly speculated that Ray's diagnosis seven years ago was especially stressful for their relationship because it occurred when they had been married only three years. As suggested by other participants as well, Kelly implied that a longer relationship history might make a PD diagnosis less likely to negatively affect relational closeness.

Shifting relational roles. In addition to sometimes leading to changes in overall relational closeness, managing PD in a dyadic context can lead to shifts in relational roles for PWPs and their partners. In some cases, for example, sleeping in the same bed can become impractical for couples because of the symptoms of PD; however, as 64 year-old Ruth explained, sleeping separately can make a marriage feel less intimate and more platonic in nature. She described the sleeping arrangement that has become routine for her and her husband Barry (who has constant stiffness in his legs due to PD), saying that it has changed their relational dynamic in some ways:

Well, I think it's just that, the changes that are happening [from PD] are stressful on our relationship sometimes. He has all these health problems from Parkinson's [so] he can't sleep in bed. We are on different floors. He has an old recliner down in the basement so he sleeps on that, at least when he wants some sleep. Because half an hour in bed and he is up; he just can't get comfortable. He sleeps in a recliner. I sleep in the bedroom. It's just kind of like, sometimes, it's like we are roommates.

Whereas some participants, like Ruth, reported feeling a shift, at times, from a romantic partnership to a roommate-type relationship, others talked about experiencing a move from "peers in a marriage" to a caregiver-patient dyad. In speaking about how his marriage to Anna has changed since she was diagnosed with PD four years ago at age 65, Doug said:

At times, our relationship is different now. More like I'm a caregiver and she's a patient. Not like we're peers in a marriage. . . . I'm a caregiver, and that can take a dominance and change the peer relationship of a marriage.

Several other partners described their caregiving role in parental terms. Helen said that, as her 80 year-old husband Walt's PD has progressed in recent years, she has begun getting him ready for the day each morning as she would a child:

I dress him in the morning and get his breakfast. It's just like—really, it's like if you had a kid, an older child that you had to take care of. That's about what it is. Except he's not an older child. But he wants his socks on when he first gets out of bed because his feet are cold. Did you ever try to put socks on a guy? It's awful. I have a devil of a time.

Helen noted that the maternal role she plays in caring for Walt primarily occurs “just during getting ready in the morning. Once I get him up and dressed, then he comes out in the kitchen and I have breakfast for him and then he is okay.” Thus, it seems that PWP and partners can vacillate between various roles depending upon the task at hand.

For some partners, taking on a parental-like role occurs not when providing physical assistance with certain tasks as Helen described, but in becoming emotionally protective over their PWP. Kelly said she has become “protective like a mom” over her husband Ray when people ask personal questions about his PD. Ray was diagnosed seven years ago at age 34 and, Kelly explained that him having PD at such a young age has attracted unwanted curiosity and questions from others:

I really quite frankly am getting sick of people. I'm protective like a mom over him. They don't need to know details, all they need to know is, “Yes, he has Parkinson's,” and if they say, “Well, how is he doing?” you know, I say, “He is having his good and bad

days,” and that’s it. But I mean, I literally have had very personal questions asked, and I just become a vicious little mom over it, and it’s just like, “No, I don’t think so; I won’t be revealing that.”

As exemplified by Kelly, sometimes shifts in relational roles can also affect interactions outside of the relationship, such as when the partner becomes protective over the PWP in fielding questions from others.

Changing relational roles can result in mixed reactions from PWPs and partners. Some participants reported no problems with moving into the role of either providing or receiving care. Others, like Ed and Tina, noted that the partner’s care was not always well-received by the PWP. Tina, a 59 year-old PWP, discussed the importance of the partner not being “just a caregiver” but, instead, also interacting like a marital partner:

He’ll occasionally talk to me like I’m his child instead of his wife, and I have to remind him, “You’ve got to put your hat on as the caregiver when it’s necessary, but I don’t want to be married to just a caregiver.”

As will be discussed in more detail in the later section on social support, giving or receiving care can, at times, be threatening to PWPs and partners because it may threaten valued aspects of their identities or relationship. In Tina’s case, being treated as a child or patient likely threatens her identity as a capable woman, as well as her perception of her marriage as an equal partnership.

Even apart from the actual exchange of care, just the label “caregiver” or “caretaker” can trigger a variety of responses because of what it can imply about the relationship between members of a couple in which one partner is deemed a caregiver. Some participants felt that labeling the partner as a caregiver was inaccurate because, despite the PWP having a chronic illness, both members of the couple may give care to, and receive care from, one another. Alice,

whose 70 year-old husband Carl has had PD for five years said, “At this point, I don’t consider myself a caretaker, no. I think he does as much for me as I do for him.” To others though, the caregiver label may go beyond seeming inaccurate or misleading to inducing hurt feelings. Lisa, a 47 year-old PWP who was diagnosed six months ago, explained that she was “shocked” when her doctor gave her and her husband Joe a video to watch on “being a caretaker” to prepare him for the experience:

They need to rephrase all that. It made me feel bad because I feel like I'm putting such a burden on my husband. [We watched the video together] and it makes you feel bad because I don't want him to be a caretaker. I want him to help me when I need it, but— When he asks me to do something for him, I do it. Is that not being a caretaker? I want to know where they get that [label of “caretaker”] from, and why they have to use that. In the video, it doesn't show them—they're putting their medication together. I have a hard time, but I can put my medicine—I have to now use the morning, noon, and nighttime [pill case compartments] to keep it all straight, and it's hard to put them in those small little squares, but I do it. Joe doesn't have to do it for me. On the video, it shows the husband and wife doing it together. Why can't we do it for ourselves?

Lisa’s comments seem to reflect her struggling with goals that are threatened by PD, such as preserving her independence and maintaining a relationship in which she is not being a “burden” to her husband. To her, labeling Joe as her caretaker likely constitutes a failure of those identity and relational goals because, if he is a caretaker then she, in turn, is altercast as someone who depends on her husband for care. In Joe’s interview, however, he seemed to attach different meanings to the term “caregiver” than Lisa. When asked, “Do you consider yourself Lisa’s caregiver now?” he replied without hesitation, “Yeah; sure.” He went on to explain, “There's

really nobody else. Her mom died a couple of years ago, and her dad died before that. Her sisters are all scattered around.” To him, the term does not seem to carry the same negative identity and relational meanings for the care recipient that it does to Lisa; instead, he described a caregiver in practical terms (e.g., as “someone who helps when she needs it”) and noted that it is a role that he is comfortable in: “My mom had a stroke when I was a little kid, and I grew up with a disabled mom. It’s natural for me to step up and help. I don’t mind.” For some partners, like Joe, the term caregiver does not seem to have negative implications because it reinforces a relational identity that they do not object to.

Experiencing changes in sexual intimacy. Several participants also cited changes in sexual intimacy as a relational challenge resulting from PD. Helen, a partner, explained that the disease makes it difficult for her to be physically intimate with her husband Walt because PD restricts his movement capabilities: “One thing that is difficult is sex. Because he can’t turn. He can’t roll over. We get in bed [but] if you want to turn over, you can’t hardly get over to that side. Physically, it’s very difficult.” PD, as well as medications to treat it, can also cause erectile dysfunction (ED). Martha said that ED was the first symptom of her husband Donald’s PD, though she did not recognize that it was a sign of an illness at the time: “I thought it was his anger towards my dad [moving in with us]. Finally, I said, ‘Don’t even try, because you’re going to get disappointed; both of us are.’” Another partner, Kelly, recalled sometimes having a similar reaction to her husband Ray’s difficulty maintaining an erection:

He gets mad because he can’t, and then after so long, even though I am fine with it, I don’t want to even try. I didn’t want to even try to because I knew he would get disappointed and upset. But he saw it like, “Well, you don’t even love me.” It’s like, it just became a big stressor.

She went on to explain that they attribute the ED experienced by Ray mostly to the medications he takes for PD. Because Ray's PD has progressed fairly rapidly since he was diagnosed seven years ago at age 34, his medication dosages have increased—and, with that increase in medications, their sexual problems have become more challenging to counteract:

I mean the disease does its role but, for us, the meds really are the biggest part. In the early part of the diagnosis and the first few years that we had, taking Viagra, things like that usually helped. And we used very small, we would cut them up—God, they're so expensive—so we would cut them into fourths. I was like, "If you don't need the whole thing, let's just use this and it makes it last longer." And now we are at the point where a full pill is not even a guarantee that it's going to help us.

In addition, some participants, including Kelly, discussed how aging might play a role in sexual changes and PD. Kelly suggested that losing sexual function due to PD is likely not as difficult for older couples coping with the disease as it has been for her and Ray (who are 38 and 41, respectively): "Most everyone is in their sixties or older and that's not an important aspect for them. . . . It's very important to us because we're very young, and that creates a whole other set of circumstances for us." She explained further,

Okay, considering I am hitting the height of my peak here, [ED] is a big problem for us. On our marriage, that has been a big stressor. . . . Because he is a man, and he is like, "I don't understand why I can't, this is not something I should be dealing with until I am in my fifties or sixties where you get issues with it not working," and things like that. . . . I tell you what, I read Michael J. Fox's book and one of the best way to describe ours is how he described his: Sometimes it's the biggest joke in the world, it really is, and sometimes you just got to laugh right in the middle of it because you have to be like an

acrobat trying new and different things and it may never work. And sometimes you just have to laugh it off; [Ray] has difficulty laughing it off. You know, he gets very upset. It's never been that it was his satisfaction, it was disappointing me. And for me, it's like, "You're not disappointing me; I could live without it if we have to." But for him that's a big part of it; that's how men feel they show their love to women. I have learned that. . . . It's amazing what you learn; you realize that life isn't a fairytale.

According to Kelly, the loss of sexual function is especially difficult for Ray because it challenges his conception of how a man his age should communicate love to his partner. Thus, in disrupting their physical intimacy, struggling with ED has shattered their previous identity as a youthful, loving couple able to engage in "normal" sexual activity.

Other participants also mentioned age in relation to sexual changes and PD. Deb, a 73 year-old PWP, acknowledged that she engages in sex with her husband Larry less frequently than she used to because the physical manifestations of PD make it challenging; however, she also seems to view these changes as a normal aspect of getting older that could occur even without the presence of PD:

When I went to the doctor not too long ago . . . he said, "You're not still having sex, are you, Deb?" I said yes. I mean, when you're this age, you don't have sex like you did when you were 20 or 30, but it's still really nice to hug in the night. So yeah, once in a while we have relations, and we do a lot of hugging. [Sex] has been affected drastically by Parkinson's, but we talk about it and I think it's okay. You know? A lot of people our age aren't as healthy as Larry—I say Larry and I—I was, and [their sex life] has been over with for 20 years.

Another PWP, Anna, also discussed the fact that sexual changes tend to occur with aging, regardless of having PD. In contrast to Deb, though, Anna mentioned that these changes are upsetting to her husband Doug nonetheless:

Physically, it's not as good, but I'm going to be 70. Some things, I wonder, "Is it age or is it Parkinson's?" A lot of the things seem to be normal for someone who's going to be 70 [but] that's gotten him—that's shaking him up."

Facing financial stress. In addition to changes in sexual intimacy, PD can result in financial challenges for PWPs and their partners. Several participants discussed the financial implications of PD as the biggest source of stress on their relationship. Paying for PD medications was the most frequently cited expense, and some participants reported that needing to maintain prescription drug and other medical coverage was the primary reason that at least one member of the couple continues to have a full-time job rather than retiring. Barry, a 66 year-old PWP, said of his 64 year-old wife Ruth: "The biggest reason she works is for the insurance. Otherwise, I'd be uninsurable, and with all this Obama stuff, it's scary for us right now. So she works to keep that—the prescriptions and all that stuff." He went on to explain,

Financially, right now, our lives are stressful. We have to be—we're making some changes in our house to make living with Parkinson's easier, and that's all—that's hard.

We've got to financially figure all that out to make it work. I'm retired. I don't work, so—I probably can't work anymore for anybody.

Another PWP, Jack, also said that him not being able to work due to PD, combined with the cost of his medical care, was a major source of stress for him and his wife Pam:

I think finances have been actually, now that I think about it, one of the biggest stresses on our relationship, because insurance only pays so much of your medical bills. That's

another area where we're still learning how to rely on God. I've been talking this whole time about God is faithful and He will provide. When it comes down to my head

[though], I'm going, "Man, I don't know how we're going to do it."

Jack and Pam's current source of income is Pam's job, and neither of them feels that her earnings are enough to comfortably support them and their three children, especially considering Jack's medical expenses. In continuing to reflect on this stress, Jack said, "Our relationship has grown in a sense, but yet, it's also been—we both wonder how are we going to do this. These pills are pretty costly."

Engaging in fewer leisure and social activities together. Another relational challenge that PD can bring for couples is a reduction in joint leisure and social activities. Many participants mentioned that, although they used to enjoy traveling as a couple, it has become increasingly difficult to do so because of the manifestations of PD. Barry, a 66 year-old PWP whose tremor makes it difficult to drive at times, explained: "Yeah, [my wife and I] like to travel and stuff, and that's kind of been put to the wayside. I can't drive distances or anything like that anymore." Another PWP, Anna, said that the unpredictability of her PD symptoms makes traveling hard to plan for her and her husband Doug:

[Parkinson's has] changed travel. See, some days you have a really good day, and some days you don't have a really good day, and you can't predict which day it's going to be. You might take the train to Chicago and have a great time, or you might get up there and can barely walk.

She went on to say that this unpredictability has turned both her and Doug off of traveling for the present time:

So I asked him the other day if there were any places he would like to go; I don't want to hold him back. He said, "Don't you like it here?" So right now, he isn't—he doesn't really want to travel right now either.

Some participants discussed their decrease in traveling as a function of not just PD, but also getting older. A partner, Paul, said that he and his wife Sharon no longer travel as much as they would like to, both due to her PD and their age: "Well, we used to camp and travel [but] part of the problem is just age. You don't do the same things at 70 you did when you were 50."

In addition to limiting travel, PD can also restrict other joint leisure activities that couples previously enjoyed on a regular basis. Edna, a 73 year-old partner, described how PD has drastically affected what she and her husband Eugene are able to do together:

We used to go to the mall and walk around, and he can't do that any longer. It's just very limited. There's just not much you can do, really. You can't go to the movies [because] he can't follow the movies. We used to like to go and do different things and we can't. . . . There's that little zoo [nearby] where they have animals that they keep, and we thought that would be good. You can see them in the fields and everything, so I thought, "We'll go over and see that." We got over there and found out that all the trails that you have to go down were gravel. He couldn't take his walker down, so we couldn't do it. You're just limited very much. He can't walk for a long period of time.

Other participants also mentioned difficulty with walking as a symptom of PD that can be especially limiting in terms of being able to continue the activities they once enjoyed as a couple. Deb, a 73 year-old PWP, said of herself and her husband Larry,

We love to go to car shows. We can't anymore. I can't walk that much. Where they have car shows—I've got a wheelchair, but you can't take it a lot of places. Yeah, there's a lot of things [we can no longer do].

Another joint activity frequently cited by participants as one that they had discontinued or reduced due to PD is going out to eat. Judith, a partner, said, "We enjoyed eating out and that, of course, has ended pretty much because it's too difficult for [Lawrence]." Joe explained that his PWP Lisa sometimes has trouble eating without spilling because of her tremor, noting that she becomes self-conscious of this in public: "I still have a hard time getting her to go out and eat dinner, 'cause it's embarrassing for her."

Finally, the symptoms of PD can sometimes bring changes in a couple's social life. Helen described how a limitation related to her husband Walt's PD has led them to socialize less with friends in their retirement community:

We always played cards. We're card players. And [our friends] play games all the time. I mean, it's people's houses, you play whatever. He can't hold the cards. Your fingers don't have the feeling. If you're playing a game with a lot of cards, you can't hold them. He can't put them in the right way to hold them. So then you're not going to play cards. So that makes it hard, because then your circle of friends—you can't do much in the evening because that's what people do. . . . Usually the routine is you go out to eat and you come back to somebody's house and you play cards. Now you can't do that.

For couples like Helen and Walt, a consequence of PD is the loss of valued social activities, which can, in turn, isolate them from others in their social network.

Experiencing uncertainty about the relationship. Finally, among some couples, PD may result in uncertainty about their relationship for either the PWP, the partner, or both. Several

participants recalled the PWP being somewhat uncertain about whether the partner would stay in the relationship after the diagnosis. Joe recalled his wife Lisa's initial uncertainty about whether he would remain committed to her after she was diagnosed with PD six months ago at age 47, noting that her fears of him leaving her were unfounded:

Shortly after she was diagnosed, I think in the back of her mind she doesn't think that I'm going to stick around. She's scared that I'm not going to be there for her. [So I've been] just reassuring her that being a primary caretaker doesn't scare me. I'm here. That's what we got married for. I think that really helped her when I told her I'm not going anywhere. It would scare some people off.

In her interview, Lisa seemed cautiously optimistic that her 20-year marriage to Joe will endure the challenges of PD. As she described his reaction to her diagnosis, it was evident that, despite his reassurances, she still has some degree of uncertainty about him staying in their relationship:

I don't know, I think he was shocked. But I'm very lucky to have him because he took it, as far as I could tell, pretty good, but it's hard to tell. He's been there so far. We'll see what happens.

Another PWP, 59 year-old Tina, also reported uncertainty about what her relationship with her husband Ed will be like in the future, but seemed less concerned about him leaving than about him resenting her:

I don't know whether I fear it [or] I expect it. I don't know. I wonder if he will grow to hate me as the years go by, due to the fact I'm so young, you know, considering the Parkinson's age usually. If I don't choke to death or die of lung cancer or something before then, you know, it's going to be an ugly life, possibly.

For Tina, wondering whether her husband will resent her as her PD advances is an unsettling source of relational uncertainty.

Like PWP, partners may experience uncertainty about their relationship stemming from issues related to PD. For instance, the medications used to treat PD have been linked to a lack of impulse control in some patients, and Kelly explained that, when her husband Ray began to engage in impulsive, destructive behaviors several years after being diagnosed with PD, she was uncertain whether their relationship would survive:

There was one point I just told him, “I can’t do this anymore if you don’t change what you’re doing.” . . . He started gambling a few years back, and started lying about things to hide things. And what it was, was that the medication he was on was heightening the gambling, the OCD. . . . And he said, “I am not discussing this.” And I said, “Let me put it to you this way: You and me will be getting a divorce, because I can’t do this anymore. I will not have you ruin the kids and me. And I don’t care what you have, you think about that when you have lonely terrible life because nobody is there to take care of you. And I am willing to.”

Kelly said that her expressing her significant uncertainty about their future together led Ray to “quit [gambling] and realize, ‘Hey, I am going to lose something if I don’t change things.’”

Communication of Social Support Within Couples Coping with PD

As demonstrated in the previous section of this chapter, the experience of PD can yield significant challenges for the PWP, the partner, and their relationship. In a relational context, an important way of managing these challenges is via social support. Therefore, this section begins with an explication of participants’ reported ways of communicating social support within the dyad. Next, complications and costs of support experienced by participants are presented.

Finally, the strategies that participants reported perceiving as effective in managing complications and costs of social support are described. Results regarding social support within couples coping with PD are summarized in Tables 1, 2, and 3.

Ways of Communicating Social Support

In coping with the stress of PD, PWP and partners may communicate support to one another in a number of different ways. Participants described supportive exchanges related to (a) assisting with activities of daily living, (b) helping the PWP stay active through joint activities, (c) providing emotional support, (d) providing informational support, and (e) encouraging perspective shifts.

Assisting with activities of daily living. Many participants discussed social support related to assistance with activities of daily living. Participants listed a multitude of activities that partners assist their PWP with, including organizing PD medications, cooking and doing household chores, driving, and completing personal care tasks (e.g., dressing or shaving). Ed, a 57 year-old partner, described the routine he has established for managing his wife Tina's medications:

Every Saturday evening, I'll get the box of meds out because she's got a basketful, and I fill up a one-week pill case, and it's got—well, now, she only takes pills four times a day. At one time, she was taking them five times a day. So I fill them up Sunday through Saturday, and at night before we go to bed, I set the pill timer for the next day. When she first started on all the medication, we didn't have the pill timers, and we were constantly late for her taking her pills. Now I take care of all her meds. I make sure when they get low, we order them. Make sure she has what she needs. If her prescriptions are running out—luckily, our mail-in prescription has a thing on there that says, “Do you want us to

contact the doctor for a refill?” so I click on that, contact them, and get a refill. So I'm pretty much responsible for making sure her meds—that we have them and that they're ready for her.

Other partners described managing their PWP's medication routine in similar ways to Ed. Helen noted that her husband Walt (who, at 80, has had PD for eight years) is completely dependent on her for this task:

Oh yeah, I do all of his meds. If you asked, he wouldn't know what he's on, which is scary. I found this little, really great case. It's three sections, just a round thing with a lid, like a compact, [for] breakfast, lunch, and dinner. So, I fill them for the day, but then take the ones out for the morning and they go [on the table]. And then he takes those. So—but one day, he took the double dose. He took it himself from the case, and he also took the one on the table that was ready for the day. He knows now that you don't take them unless I tell you, “These are the ones you're going to take,” because he couldn't understand how to do it himself. It's complicated.

Helen's husband Walt expressed appreciation for her assistance: “It helps a lot. Whenever it comes time to take medication, she takes care of it for me.”

Partners may also help their PWP by taking on additional household tasks (especially ones that have become difficult for the PWP to complete), such as cooking or cleaning. Cheryl, a 76 year-old PWP, said that, since her PD diagnosis a year ago, her husband Todd has been conscious about encouraging her to relax and work less around the house: “I think doing meals is part of it. He'll say, ‘You sit down,’ and he'll go ahead and do dinner. He does a darn good job. He's really sweet about that.” Other participants echoed the idea that the partner has taken on more responsibilities around the house as a result of the PWP's illness. For instance, 73 year-old

PWP Deb said of her husband Larry: “He’s been doing one room at a time, doing extra stuff. He cleaned those curtains and cleaned that window this morning.” Doug, whose 69 year-old wife Anna has PD, said, “When things need to be done, I do more. Mechanically, the logistics of living. She does the laundry, but I tend to clean now [whereas] she did more before.”

Many participants also mentioned the partner helping the PWP by doing all, or the majority, of the driving. As previously mentioned, PD can affect a person’s ability to drive (e.g., by reducing concentration and response time) and, as a result, the PWP may become dependent upon others for transportation. Alice, a 69 year-old partner, explained,

I do more of the driving now. Part of that is not necessarily—if he has his tremor, then he actually can drive pretty well, but it’s when he takes that medication and he gets sleepy that it’s a problem. We make certain that he doesn’t drive in those times. We usually go in my car, so I just jump in the front and he jumps in on the other side.

Finally, some participants discussed the partner helping the PWP with personal care tasks. Edna said that she helps her husband Eugene, a 73 year-old PWP, with activities such as shaving and getting dressed each morning. She recalled,

He gave up a long time ago trying to dress himself. He’ll get both legs in one of the pant legs. He puts both feet in the same leg or he tries to do that. He’ll holler for me to come. Another task that some PWPs, particularly those with advanced PD, may require help with is using the bathroom. Walt, an 80 year-old PWP, described the system he and his wife utilize to indicate that he needs help with this activity:

If I have to go to the bathroom, sometimes you can’t wait. I don’t want to wet my pants. I keep a little squeeze horn by me. I’ll use the horn and squeeze it. She’ll answer my request to take me to the bathroom.

Although the most frequently cited examples of assistance with activities of daily living entail the partner helping the PWP, several participants noted that the reverse is sometimes true as well. Sharon, a 71 year-old PWP who has had PD for over twenty years, explained,

I realize that Paul's my caregiver. That's what people call him. But I feel like we really do take care of each other. He's had the flu or something, where he's coughing all the time. And so, in times like that, I look after him.

Another PWP, 76 year-old Cheryl, spoke of the communal approach she and her husband Todd take in completing daily chores around the house and yard:

It takes both of us. If something happened to either of us, we couldn't keep up with this house. He's got a hip—it's just this deterioration, and he's probably not as zippy as he could be, either. Like I said, it takes both of us.

In some couples, the PWP is much more dependent on the partner for assistance with daily tasks than vice versa; however, in other cases (e.g., Cheryl and Todd), the PWP and partner are highly interdependent.

Helping PWP stay active through joint activities. In addition to assistance with daily tasks, social support can sometimes take the form of the partner helping the PWP stay mentally and/or physically engaged through joint activities. Some participants described playing games (e.g., Scrabble) or doing crossword puzzles together in an attempt to maintain or sharpen the PWP's mental acuity. Several partners reported a general desire to help keep their PWP physically active, saying that the activity itself matters less than the fact that the PWP is engaged in some type of movement. Alice said that she and her husband Carl, a 70 year-old PWP, have the motto of, "Use it or lose it," to refer to the physical deterioration that can occur from

inactivity in PWPs. She explained that she often creates joint activities for the two of them, with the intent of keeping Carl moving:

I'll say to him, "Let's go pick up branches." I think that's good for him. He needs to not just sit and watch the History Channel, which he does. He loves to watch the History Channel. But he knows that he should move, and it is true. I've asked him now—usually, I just went shopping. He would never go. He was always doing something or at work. Now, sometimes I'll say, "Why don't you come with me?" It's good for him to walk around the store, that kind of thing, so he has done that with me.

Even when a joint activity has the primary purpose of engaging the PWP, it may be enjoyable and beneficial to both members of the couple. Of the exercise routine she and her husband, 80 year-old PWP Walt, follow, Helen said:

We go to [a fitness center] three times a week. He loves going. He really enjoys it, which is good. And then I do the exercises with him, which is good for me, too. It's a good way to start our day.

Helen went on to explain the ways in which she assists Walt during this activity:

He exercises on the Nautilus machines, and I set them. He can't do it because you're on machine number one, and you have to pick three pounds or thirty pounds or whatever and then do it. Mentally, I don't think he could read it and do it. I shouldn't say read it. He could read it, but I don't know whether he'd comprehend it. He can get himself in the machine. Getting out of it is a little more difficult. I do one [machine] and he does the other, and then I'll run over and help him get out if he needs it.

Although Helen is clearly providing support to Walt during this activity, she is also participating rather than just helping him. As a result, the activity serves multiple purposes beyond Helen

helping Walt exercise (e.g., it also provides an opportunity for her to exercise and a chance for the couple to engage in a satisfying activity together).

Providing emotional support. Participants also described attempting to help one another by communicating emotional support. It is common for both PWPs and partners to experience a range of negative emotions (e.g., fear, anger, sadness) in response to the diagnosis of PD, and members of a couple often turn to one another for emotional support at this time. Denise recalled her husband Greg's PD diagnosis (which occurred four years ago when he was 59):

You know, initially, I was more frightened than him, and he comforted me, that you know, that he was going to get the best medical care and take the best care of himself and it's in God's hands, and worrying about it isn't going to make it any better.

As demonstrated by Denise's remarks, sometimes the partner reacts more negatively to the diagnosis than the PWP. As a result, the newly diagnosed PWP may be in the role of providing support to his or her partner. In other cases, the reverse is true, as noted by Jack, a 47 year-old PWP:

At that moment [when I was diagnosed], my wife was strong, which seems to be the general case for couples—that when one is weak, the other is strong. She was right there with me, giving me comfort. I think she got a little teary-eyed, but she didn't break down at that point. I know since then she's had her times.

In addition to health concerns, a PD diagnosis may yield uncertainty about a couple's relationship; therefore, receiving reassurance about a partner's relational commitment may provide significant emotional relief. As previously mentioned in regard to relational issues, a partner, Joe, recalled providing this type of emotional support to his 47 year-old wife Lisa shortly after she was diagnosed less than a year ago:

I think in the back of her mind she doesn't think that I'm going to stick around. She's scared that I'm not going to be there for her. [So I've been] just reassuring her that being a primary caretaker doesn't scare me. I'm here. That's what we got married for. I think that really helped her when I told her I'm not going anywhere. It would scare some people off.

After the diagnosis, emotional support continues to play a central role in coping with PD for many couples. Some participants spoke of the importance of listening and allowing the other to express emotions. A partner, Ruth, described conversations with her PWP, 66 year-old Barry: "He'll say, 'I don't like what's happening to me.' And I listen." Several participants also mentioned the partner helping the PWP calm down when he or she experiences frustration (or other negative emotions related to being limited by PD). Kelly explained that her husband, 41 year-old Ray, often becomes upset when doing household projects because having PD severely inhibits his dexterity. She recalled the recent experience of him completing an addition to their house:

Sometimes I would hear curse words coming from that room and it was because he was having difficulty working with his hands. So I would take him a beer and say, "Why don't we sit down and talk for a little bit and feel better and whatever?" We would just talk and we would relax for a while. And you know what, usually, he would get up and he would go finish, or I would say, "Why don't we call it a night?"

According to Kelly, just the act of taking a break from the frustrating task and talking is often enough to help calm Ray's negative emotions.

Emotional support can also be crucial in helping the PWP or partner cope with anxiety-producing medical decisions. Married couple Paul and Sharon each recalled leaning on one

another for emotional support—as well as relying on their faith and the prayers of their support network—before making the joint decision for Sharon to have Deep Brain Stimulation (a surgery done to reduce the signs of PD). Paul said,

When we were going through this, we sat there and talked about it a lot. “What do you think?” “No, I don’t want another hole in my head. I don’t want to die.” So we discussed it very well and we prayed about it a lot. We both go to church and feel strongly in our religion, and we had a lot of people praying for us, and once we decided to do it, there was no doubt.

For Paul and Sharon, being able to talk to one another about their fears regarding Deep Brain Stimulation was one crucial step in their mutual decision to move forward with the surgery.

Providing informational support. Another way that PWPs and partners often attempt to help one another is by providing informational support. Participants frequently mentioned exchanging informational support in the form of sharing information from media sources (e.g., the internet, newspaper, or television). Several participants, like 72 year-old partner Paul, reported watching television programs related to PD with their spouse: “Just last night, Michael J. Fox was on Letterman talking about Parkinson’s, and we stayed up and watched him.” Many PWPs and partners also discussed reading and passing along articles about PD-related research studies to their significant other. Alice, a 69 year-old partner, described the informational support that she and her husband, 70 year-old PWP Carl, exchange with one another:

We talk about what’s happening in the research a lot. Every time we see something, we share it with each other. I’m always looking if something comes across the internet or something, some kind of research. He’s trying to find out more about that, too.

Participants also commonly reported sharing information related to activities for PWPs (e.g., support groups, exercise programs). Ron, a 68 year-old PWP, said,

[My wife] Bonnie saw it in the paper that [the local fitness center] had programs specifically for people with Parkinson's: Parkinson's exercise classes. That was one of the first things that we did. Bonnie saw it in the paper, and I took them.

PWPs may also involve their partners in their exercise programs by sharing related information with them. Warren, a 67 year-old PWP, said, "I found some exercises on the internet back in the summer. I talked to [my wife] about it and I printed them out, actually, so she could read about them, too."

Many participants reported informational support being particularly prevalent in the early stages of the disease (often before a diagnosis had even been made). Kelly, a 38 year-old partner, said she actively sought information about her husband Ray's symptoms because doctors were unable to accurately diagnose him for two years:

I would say two years prior to the diagnosis, we went through several different things. . . . He had what he thought was ADD [Attention Deficit Disorder], because he was having trouble remembering things, things didn't seem to come naturally anymore, and he worked in sales at the time. He had ADD medication and that didn't seem to work. And then we started noticing he was having difficulty holding things in his hand. . . . And then when we went in, they sent him to a company doctor for his hand, because they thought his hand had carpal tunnel syndrome. They actually did surgery on his right arm, thinking that's what it was, and it did nothing but get worse. I finally took him back to our family doctor. He could not diagnose and figure out what was going on. That's then when I took it upon myself to get on the internet and I started researching diseases with tremors. And

he would have one or two symptoms. When I came upon Parkinson's though, I said, "Oh my God, this is the last two years of our life." I told him, "You've hit every symptom on here at any given time over the last two to three years." I just simply called a family doctor and said, "I want to be referred to a specialist." . . . So we went to [hospital name], we saw a neurologist up there—very nice guy—and he did all these physical tests there in the room, and he said, "Your wife is correct, you have classic Parkinson's."

In short, a significant number of partners, like Kelly, recalled being heavily involved in the diagnosis process by noticing their PWP's symptoms, searching for information online, and providing information to the PWP as well as to medical professionals.

Another way of communicating informational support that was commonly cited by participants was the partner providing advice to the PWP. PWPs may be concerned about a particular symptom and turn to their partner for input. For instance, of his 47 year-old wife Lisa (who has had PD for less than a year), Joe said,

If something's really bothering her, like if she's having problems doing something [because of PD], we talk about it. She talks about it to me and says, "I'm having trouble doing this." My first response is, "Did you take your pills this morning?" or if it's something I'm really concerned about, I'll say, "Let's get in and see your doctor. This is a definite change that we need to monitor."

In addition to gaining insight about whether or not an impromptu medical visit is warranted, several PWPs said that it can be particularly helpful to review symptoms with their partner before going to a regularly scheduled doctor's appointment. Ron, a 68 year-old PWP, explained that his wife Bonnie often offers helpful advice about which symptoms to stress the most at his appointments:

I see the neurologist usually every six months, and before I go, I type up a thing saying what my new symptoms are, what my concerns are, and Bonnie helps me with that. Sometimes, she has a different view of what concerns I should be—like the last time, I thought my main problem was constipation, which was one of the things, and she said well, that was a problem that we were dealing with, but I was getting tired and she thought that was my primary symptom. She thought it was more important to do something about that, and she was right. I was sort of napping in the afternoon. I'd get up from a nap and want to go back and have another nap. She said we really ought to tell the doctor that, so I put that on [the list], and the doctor prescribed a drug which has seemed to take care of it.

Ron's comments reflect the fact that, because partners are in the position of observing their PWP's symptoms on a daily basis, they can sometimes offer valuable information related to assessing the PWP's condition.

Along with communicating information to help the PWP prepare for medical appointments, many participants reported that the partner actually accompanies the PWP to medical appointments to help provide, listen to, interpret, and remember information. Unlike the previous example (in which Ron described working with his wife to jointly compile a list of symptoms *before* his medical appointment), some PWPs and partners both provide information about the PWP's symptoms *at* the medical appointment itself. Kelly, a 38 year-old partner, said that she and her husband Ray are a "team" at his doctor's appointments because she is able to provide information on symptoms that he has not noticed and vice versa:

Because he doesn't see himself, there are a lot of [symptoms] he doesn't see. And it's a funny thing: When we go to the doctor, I sit there very quietly, I let the doctor ask Ray all

the questions, and then Doc will turn and look at me and he goes, “Okay, now?” So, I’ll say, “Okay, he is shuffling his feet more” or “He is doing this” or “I am seeing this, I am seeing that.” And, there’s things that my husband says that I don’t realize because I am not the one using my hand to brush my teeth; I am not the one experiencing it.

Other participants said that the partner accompanies the PWP to medical appointments because the PWP does not ask enough questions or provide a sufficient amount of information. Carol, a 75 year-old partner, said she first went to the hospital with her husband Ken when a PD-related fall landed him in the emergency room. While there, she was surprised by how little information-seeking Ken did. She explained,

So then I think I heard how [Ken] was less than forthcoming with questions and that kind of thing, and I think, “Oh boy, I need to start going,” and he doesn’t mind at all. So I go and listen and jump in when I feel he isn’t telling the whole story.

In his interview, Ken said that he finds it helpful for Carol to come to his appointments because she is more thorough at gathering information than he is:

It helps ’cause [before] I would go in and say, “I’m feeling fine.” I’ve got a couple of questions and I go, and she has a lot more. I think it’s just I feel like I’m overreacting [if I ask a lot of questions], so I just bring up two or three questions and that’s it.

Besides gathering and providing information, partners may also help PWPs at appointments by listening to, interpreting, and later recalling information. Lisa, a 47 year-old PWP, said, “I would never go by myself to an appointment. I have my husband go with me because I need more than just my ears and my understanding.” Similarly, Carl, a 70 year-old PWP, said,

My wife's gone with me to every trip I've made to the neurologist because I like to have a second person present when the symptoms are being discussed so that I can discuss with Alice later what we think the neurologist said. I don't always come out with the same impression that she does.

Just as interpretation of medical information be a challenge, so too can remembering what was said during the appointment. Ruth, a 64 year-old partner, noted that having either her or their daughter at her husband Barry's appointments is important because of his difficulty with memory: "He forgets the doctor's answers. So one of us is there to know what's going on at all times."

Encouraging perspective shifts. Finally, some participants reported social support related to the partner helping the PWP with shifts in perspective. As previously discussed, PWPs (particularly those who are relatively young) may struggle tremendously with the reality of being inhibited by PD. A partner may try to help them come to terms with these limitations by encouraging acceptance. Jack, a 47 year-old PWP, reflected on this type of support, after discussing how the disease has affected his ability to play sports. He spoke of his wife Pam, saying, "I think that one thing that Pam wants me to do more of is allow myself to have some frailties and to feel certain ways. She encourages me to accept things." During her interview, Pam explained,

Some days, he's tired so that's the thing: giving him permission to take naps and being okay with that. He'll be like, "I don't need a nap." I say, "Yeah, you do, and it's okay." So he's allowed himself to take naps, whether it's at noon or whenever. He works it into his schedule.

Other ways of helping with perspective shifts might come in the form of the partner reframing potentially identity-threatening changes, such as starting to use a walker or cane. Ruth described the reaction her husband Barry, a 66 year-old PWP, had to his doctor's suggestion of using a four-pronged cane. Although Barry has fallen a number of times because of PD-related balance problems, he was initially resistant to the idea of a cane because of what he thought it implied about his stage of disease. Ruth recalled,

As we left the doctor's, he says, "Am I really that bad? I am not ready to do that; I don't need that." I said, "The doctor didn't say you have to get it," and I waited for him to bring it up again early this week. [Then] I said, "It's not that much money. If you feel safer with it, even just walking from the bedroom to the living room, you could just use it in the house. Work yourself into it, as far as that goes. If you're walking around outside and it gives you a little more stability, maybe you will like it."

Ruth went on to say that Barry "has to work into things;" therefore, she did not want to force the issue with him. Instead, she reframed the cane as something that he could simply elect to try temporarily and later discard if he wanted.

Complications and Costs of Social Support

In addition to yielding insight about ways that PWPs and partners communicate support to one another, results of this study demonstrate that these supportive attempts can entail challenges. Participants reported the following complications and costs of social support: (a) partners' differing approaches to coping can make support difficult, (b) support can be threatening to the PWP's identity as independent/capable, (c) support can be interpreted as controlling, (d) support can place an unwanted emphasis on the disease, (e) support can bring

concerns about burdening the other, (f) support can lead to dependency, and (g) support can be draining.

Partners' differing approaches to coping can make support difficult. Many participants noted that, at times, communicating support is complicated by the fact that they have a different approach to coping with PD than their spouse. More specifically, members of a couple may have differing attitudes; varying desires for, or interpretations of, information; and incongruous preferences for talking about the disease. Deb, a 73 year-old PWP, explained that she and her husband Larry have disparate ways of viewing the world in general: "The only bad part about Larry helping me is that his cup's half-empty. My cup is half-full all the time and his is half-empty." She went on to provide an example of how these varying perspectives can complicate PD-related support:

He told the doctors one day that I was having trouble with my words and I was having trouble remembering things, and they decided I might be losing my mind, and so anyway, they gave me tests for Alzheimer's. I told them I was fine, and they said, "No, we'll just go ahead and do this test." So they did, and when they finished—I didn't miss a thing—they said, "You're perfect," and I said, "Go out in the hall and tell my husband." He and [our daughters] were sitting out in the hall. So they did, so Larry said okay. So now, other than when I specifically say, "Go in with me," he stays out in the waiting room because his attitude's different than mine. But that's just the way he thinks.

From Deb's perspective, Larry's more pessimistic outlook clouds his judgment about her PD symptoms and prognosis because, unlike her, he is expecting the worst. Thus, for some couples, supportive attempts (e.g., the partner accompanying the PWP to the doctor) can be problematic because of discrepant attitudes.

Furthermore, these varying attitudes can affect the ways in which both members of the couple seek (or avoid) and interpret information related to PD. Ed, a 57 year-old partner, explained that he would rather avoid most information about PD because reading the “horror stories” online would interfere with his desire to “not worry about something that might not happen.” This preference, however, clashes with his wife Tina’s inclination to learn as much as she can about the disease and share this information with him:

When she got her diagnosis, she was on the internet. She was writing to the American Parkinson’s Association, getting this literature. She was reading everything she could on the internet. Well, she was telling me some of these horror stories. I didn’t want to hear it. She’d tell me, she’s got a 30 percent chance of developing dementia. Okay? That means she’s got a 70 percent chance she’s not. I’m looking at the 70 percent. She’s looking at the 30. She’ll say, “Yeah, you’re going to stick me in a nursing home” and I say, “No, I’m not.”

The couple’s conflicting preferences regarding information present a challenge because Tina, age 59, seems to be frustrated by her perception that Ed is not acknowledging how severe her PD may become in the future. She explained that she feared he was in denial about her disease and described “forcing him” to read PD-related materials one day:

He really didn’t want to read about it, and I’m a “if something’s broken, let’s fix it or find out about it” person, and he is not that kind of person. And so several months went by and I had some literature and I wanted him to glance through it. It was aimed at a caregiver, and he went straight to the back, where it described the end stages, which was the very worst thing he could have done. We eat fish a lot, and we only fish together, and it’s a big part of our lives, and he looked at me and he said, “So what am I supposed to do

with you?” I said, “When?” “Well, you know, if I have something to do.” I said, “Like what?” He said, “Like go fishing.” And I just calmly looked at him and said, “Well, I guess you take me to the adult daycare,” and the next day I blew up. He was angry because I was forcing him to learn some information he wasn’t prepared for.

As evident in this example, when a couple has mismatched information preferences, informational support can be extremely challenging. Both members of the support may face the dilemma of either each adhering to their own preferences even though they differ from their partner’s, or attempting to change their own or the other’s information-related behaviors. In Tina’s case, “forcing” Ed to read information he was not ready to face resulted in him retaliating by being hurtful in his comments to her.

Similarly, some participants also described challenges related to having different preferences than their partner in terms of talking about PD. Kelly recalled the difficulty of wanting to talk about PD when her husband Ray (who was diagnosed with PD seven years ago at age 34) did not want to:

What angered me is—I am one of those people, “Let’s fix it, let’s organize it, let’s take care of it, let’s plan, let’s do this, let’s do that.” [Because of PD], our whole retirement plan just changed in the blink of an eye. He didn’t want to talk about it. And I mean to me, the first five years was the most crucial to get ourselves set and he was not wanting to talk about it. It’s not till the last six months that he has opened up to talking about Parkinson’s at all.

As demonstrated by Kelly’s remarks, because talking about PD (e.g., discussing information and jointly making a plan) is viewed by some people as an important way of coping with PD, it can be challenging when partners’ preferences for communication are discordant.

Support can be threatening to the PWP's identity as independent/capable. Another difficulty of support is that it can sometimes threaten an individual's identity as independent and capable. Therefore, partners may face the dilemma of wanting to offer their PWP help, yet struggling to find a way to do so without implying that the PWP cannot complete the task independently. Pam, a 51 year-old partner, explained this dilemma in regard to her husband Jack, a 47 year-old PWP:

Sometimes, when I try to help, he'll come back with, "What, you think I can't do this?"

Like driving, especially. We drove back last Sunday from [a hiking spot two hours away]. I was exhausted, and I'm thinking, "If I'm exhausted, he must be *exhausted*." I just offered, like, "I'd be happy to drive home," and he was like, "No, I'm fine." A lot of times when I do offer help, it's like, in his mind, I'm saying, "You can't do this, but I can." I've been trying to work through that.

In addition, several partners noted that providing support can be complicated because, at times, it may be difficult to know when the PWP wants to act independently and when he or she wants help. Of this dilemma, Kelly, a 38 year-old partner, said,

It's like raising teenagers: One day, one moment, they want to be a teenager and they want to be independent, the next moment they want to be your little kid. And sometimes it's hard to read that. That's exactly what you're going through with a Parkinson's patient.

Thus, at times, some partners (like Kelly) may feel they face the dilemma of either supporting the PWP (e.g., via tangible assistance) and running the risk of threatening his or her sense of independence, or *not* helping and taking the chance that the PWP wanted assistance in that circumstance.

Support can be interpreted as controlling. Participants also noted that the exchange of support is sometimes complicated by the fact that an attempt to help can be interpreted as controlling. Warren, a 67 year-old PWP, said that he has become frustrated at times with his wife Teresa's behavior at his doctor's appointments:

Sometimes, she jumps to conclusions a little bit about how I'm doing and that kind of thing. One time we went to Dr. [name omitted], and she was kind of putting words in my mouth, and I was saying, "Now wait a minute. Let me talk here." I don't mind, but I do kind of like being in charge of my own medical interview kind of thing.

As previously discussed, going to medical appointments with the PWP can be a valuable form of social support; however, as demonstrated by Warren's comments, a PWP may feel undermined if he or she has the perception that the partner is trying to take control of the appointment.

Other PWPs, like 69 year-old Anna, also discussed instances in which they felt their partner has acted in a controlling manner. Of her husband Doug, Anna said, "He gets sometimes, I think, a little controlling of me—like bosses me a little bit. I think, 'Well, now, is that deserving?'" She provided an example:

Something I have trouble with a lot, and he gets mad about this, is I lost a lot of weight because I'm on a lot of medicine. I try very hard to eat, but I don't eat enough, and he gets real upset about that. He's a good cook. He'll say, "What are you hungry for?" and he'll fix it. For him, he doesn't care so much about what he's gong to eat as that I eat, and so he gets upset about that. It's kind of—I fill up very fast. I've been to a nutritionist, and I try to eat enough, but I don't really eat enough. I think that upsets him the most.

Sometimes he can get—just lose it and get really upset.

In short, despite her best efforts, often Anna is not able to eat as much as Doug would like. In this way, in addition to being viewed as signs of caring, the meals he makes for her may be seen by Anna as creating an obligation for her to fulfill (i.e., she feels she needs to eat “enough” or risk upsetting him).

Support can place unwanted emphasis on the disease. As previously mentioned, support can be complicated by the fact that members of a couple sometimes have different preferences for talking about PD. One member of the couple may seek to provide and/or receive support in the form of talking about PD, but be unsuccessful because of their partner’s desire to avoid this topic of communication. Several PWPs who, in contrast to their partners, expressed a preference for not talking about PD, said that they tend to avoid PD-related conversations because they do not want to focus on the unpleasant topic of their illness. Laura, a 67 year-old PWP, explained: “I just try to deal with it myself, whatever’s going on. I’m a Pollyanna, so I don’t particularly want to talk about it sometimes. It’s bad enough having it.” In addition to not wanting to focus on the disease because they consider it an unpleasant topic, some PWPs may resist support because they do not want the disease to become a central part of how others view them. Of her husband, 47 year-old PWP Jack, Pam noted, “He just wants to be seen as Jack, not Jack with Parkinson’s.” Receiving support (e.g., in the form of frequent inquiries from Pam about how he is feeling) may interfere with that goal by placing an unwanted emphasis on the disease.

Support can bring concerns about burdening the other. Some participants discussed the possibility of burdening the other as a significant concern related to support. This issue may be especially salient among couples in which both members have health problems. For example, 76 year-old PWP Cheryl said of her husband Todd (also 76),

He is really good about helping. It bothers me though because sometimes I think he hurts worse than me with that hip. He's just really stiff right now. I don't know if it's arthritis.

He hobbles around a little bit, and here I am on the couch.

As Cheryl alluded to in her remarks, when a partner *provides* support at a time that he or she may seem in need of *receiving* help, it can bring up feelings of guilt for the support recipient.

In addition to PWPs, partners sometimes reported this concern about imposing on the other. For example, 64 year-old Ruth discussed feeling overwhelmed and scared about the future since her husband Barry's diagnosis two years ago. She expressed a strong desire to talk to Barry, her closest confidante, about these feelings, but said that she did not want to be a burden to him: "I don't want to worry him." Partners, such as Ruth, may have the inaccurate perception that their support needs should take lower precedent than those of the PWP. As a result, concerns about burdening the other may lead them to not seek support.

Support can lead to dependency. Another potential cost of support is that it can lead to dependency. Several participants expressed the concern that, if a partner constantly provides tangible assistance to a PWP, the PWP may become incapable of completing certain tasks. Sharon, a 71 year-old PWP, said, "I want to keep on trying to do things myself. I'm afraid—not afraid but—if you ever stop, maybe you wouldn't be able to get going again." Other participants worried that continually receiving support might result in a PWP feeling less motivated to act independently. Walt, an 80 year-old PWP who was diagnosed eight years ago, acknowledged that, at times, he asks his wife Helen for help when he does not need it:

Maybe it's my fault more than anything. I'll ask her to go get me something or do this when I could do it myself. I don't do that all the time because I've got to get up and move around myself.

In her interview, Helen said that Walt has become more dependent on her in recent years, both as a result of the disease advancing and him becoming accustomed to her continuous help:

I'd say in the last two years, probably, [taking care of him] has been harder, because now he's become dependent. It's like in the morning, he can't dress and undress too well.

Sometimes he'll surprise me. If I go out and have breakfast and he's still in bed, I'll hear him and I'll wait awhile. Once in awhile, he'll try to dress [but] putting your pants on, getting your belt, zipping your zipper, putting your arms in—that part is difficult. He can do it, but it's very slowly. I'm the opposite. I'm speed-o, so I think sometimes I tend to do more than I need to and not let him do it, because now he's getting to be, “Well, I need some toast.” He said, “I think I'll have some pie,” and I said, “Can you get up and get it?” I feel bad because it's hard for him to get up, so then you don't want him to have to get up to get it. Because then I feel guilty if I don't help him. That's the hard part for me.

As evident in Helen's comments, deciding whether or not to assist a PWP with tasks can be dilemmatic for the partner: Helping the PWP may lead him or her to become dependent, yet *not* helping may result in watching the PWP struggle and, in effect, yield feelings of guilt.

Support can be draining. A final cost frequently mentioned by participants is that providing support can be draining. As previously noted, having a spouse with PD often means taking on increased responsibilities (e.g., caregiving tasks or additional housework). In regard to the additional responsibilities she has accumulated since her 41 year-old husband Ray was diagnosed with PD, Kelly spoke of being overwhelmed and said, “It's all on me now.” Another partner, 64 year-old Doug, described the challenges that caregiving can bring. He recalled a difficult period soon after his wife Anna was diagnosed:

The caregiver—one of the challenges, no matter what, is an impatience with the person because you yourself are emotionally stressed. So then you become impatient and negative. That kind of thing. So I finally just went to my doctor, and he referred me to a psychologist. For a year, I took some antidepressant medicine, which was quite effective, I must say.

For partners like Doug, the stress of providing support can be both a personal and relational strain that can exacerbate other emotional challenges (e.g., coming to terms with the partner's diagnosis).

Strategies for Effectively Managing Complications and Costs of Support

As evident from the previous subsections, results of this study not only elucidate ways in which PWPs and partners communicate support to one another, but also delineate complications and costs that can be associated with supportive attempts. In this final subsection, the strategies that participants recalled utilizing in an effort to mitigate these challenges of support are reported. Specifically, PWPs and partners discussed effectively managing complications and costs of support by (a) framing partners as equals, (b) relinquishing control, (c) having the partner follow the PWP's lead, (d) using humor, (e) seeking/providing support indirectly or subtly, (f) having an outlet, (g) using nonverbal cues, and (h) taking the other's perspective.

Framing partners as equals. Some participants noted that framing PWPs and partners as equals can be an effective way of minimizing the threat to a PWP's identity that can occur with support. When Carol noticed that her husband, 78 year-old PWP Ken, was starting to make significant errors in calculating their finances (e.g., balancing the checkbook, completing tax records), she did not point out the mistakes as likely resulting from the mental symptoms of PD. She recalled that instead: "I just said, 'You know, sweetheart, you've been so busy; you've been

doing so much in the yard lately. Would you mind if I just did the checkbook this month?”

According to Carol, she hoped that, by casting her and Ken as equal partners both engaged in taking care of household chores, this shift in tasks would seem less threatening to her husband.

She went on to say that Ken did not seem to mind at all:

So when I finally said, “Why don’t I do it next time?” he said, “Oh, okay.” And I thought maybe he would feel like I was taking something away from him, but it was like no big deal, just, “Oh, okay, sure.” And I think [his reaction] was related to me—to how I approached it. And so now, I finally do [the checkbook]; I have done it for a couple months.

By acknowledging, in her offer of assistance to Ken, how hard he had been working in the yard as opposed to focusing on the errors in his calculations, Carol framed her husband as someone who contributes to the work of maintaining the household. In this way, casting partners as equals when providing support can minimize or even eliminate a threat to the PWP’s identity.

Relinquishing control. In addition, several participants discussed making a decision to relinquish control as a strategy for managing costs and complications of support. One way of relinquishing control is for PWPs to “let go” of certain tasks or activities and accept help. For example, 68 year-old PWP Ron said he had learned to “take it in stride” when his wife Bonnie offers to perform activities he formerly did. He said, “It’s just easier to let her drive. Taking it in stride is [my way of] coping with it.”

Partners reported attempting to relinquish control as well. Because a challenge of support is that it can be interpreted as controlling, some partners discussed not wanting to be a “nag.”

Pam, a 51 year-old partner, said of her relationship with her husband Jack,

I decided that I wasn't going to become this nagging wife that says, "Did you do your exercises?" I wanted him to own it. After three months of being on the first dose [of PD medication], he threatened to stop. He was like, "This isn't helping. I'm thinking about just not taking anything." And I tried so hard not to overreact. I think, at that point, it was like, I realized, "I can't be everything." I guess it's a commitment to say—and I've told Jack this: "I'm at your side 100%, but I will not do this for you." I told him that right in the beginning: "I will not take your medicine for you. It's not going to do me any good. And I'm not going to put it on the table and push it down your throat, and I'm not going to do your exercises, period."

For Pam, relinquishing control entailed recognizing what was and what was not within her power to do to help her husband. In effect, she avoided being seen as the "nagging wife," and freed herself from the likely frustration and strain of trying to "be everything" for him. Furthermore, by letting go of control, she allowed 47 year-old Jack the space to eventually find his own PD management plan. She explained,

He was really discouraged, so we went and had a family vacation, and that went fine, and then we got back, and the plan was to go see the doctor when we got back. [The doctor] doubled his medication and gave him a little pep talk about getting into yoga or doing some exercises, and since that visit, he's a changed person. He gets up every morning, and he has this little exercise routine, and it's his own. He owns it. The first week that he did that faithfully, it just made me cry, because that's what I was praying for, that he would come up with his own plan. I'm here to help. I'm here to encourage. But I didn't want it to be my plan dumped on him.

Having the partner follow the PWP's lead. Participants also frequently said that an effective way of managing costs and complications is for the partner to follow the PWP's lead regarding when he or she wants support. For many couples, this means coming to an understanding that the partner should not provide tangible assistance unless the PWP asks for it. Lisa, a 47 year-old PWP, explained,

The things that would bother me are people who would baby me. I wouldn't want that. I can still do everything. I just may not do it as fast as you would like. Buttoning a button takes a lot more time. Going to the bathroom takes a bit longer because it takes a little bit longer to get my zipper zipped up. If you see me struggling, let me struggle for a little bit. If I need your help, I'll ask for it. My husband doesn't help without me asking. He'll just walk on by. He doesn't make a big deal out of me struggling with things because he knows I don't want him to.

By providing tangible support only when the PWP asks for it, the partner may be able to avoid or minimize potential challenges of support (e.g., the PWP becoming dependent, or having his or her identity as a capable individual threatened).

Similarly, some participants also discussed a preference for the partner to not communicate about PD (e.g., to provide informational support) unless the PWP brings it up. Of her husband Lee, Julie, a 67 year-old partner, said,

I follow whatever he wants to do, and whatever he wants to talk about—follow his lead. I don't want to concentrate on [PD] if he's not willing, and I don't think he's willing to. If he wants to talk about it—know more about it— we will, and if he doesn't, I'm not bringing the subject up.

As alluded to by Julie, this management strategy may help prevent the possibility of the partner placing an unwanted emphasis on the disease or providing information that the PWP would rather not know.

Using humor. Another way of managing costs and complications of support is through the use of humor. For example, 75 year-old partner Carol said that when she wants to communicate concern or advice about a PD-related issue to her husband Ken, she uses “loving teasing.” She explained,

We have never really had deep discussions about how we feel about pretty much anything. That’s just the way people are, so that’s not unusual that he doesn’t talk about it. We kind of make fun sometimes in a light manner. I don’t mean making fun, that’s a bad way to say that. When I say make fun, I more mean kind of banter back and forth—loving teasing, that’s it. We have a friend and I asked, “Does your wife ever give you directions?” He doesn’t have Parkinson’s, but he says, “Oh I get *a lot* of guidance.”

[Laughs] So now, that’s what [Ken and I] refer to it as—our joke is, I’m giving him a lot of guidance here.

When asked to provide examples of their use of humor related to PD, Carol recalled, “I’ll say, ‘Pick up your feet, come on,’ or ‘You sound like an old man.’ Or when he’s driving, he veers to the left so I’ll say, ‘Oh boy, your lane! Come on, let’s drive!’” Couples like Carol and Ken, who tend to avoid having serious discussions in general, may feel more comfortable talking (e.g., giving advice or “guidance”) about PD in a light-hearted manner because it is in line with their typical relational dynamic. In addition, partners may feel that advice given in a humorous manner is less likely to embarrass the PWP or make him or her feel intruded upon because it can be brushed off as a joke.

Seeking/providing support indirectly or subtly. PWPs and partners may also manage complications and costs of support by being indirect or subtle when seeking or providing assistance. Being indirect may be especially useful in helping the PWP save face when needing support related to a potentially embarrassing or sensitive task. Helen, a partner, described her husband Walt's indirect way of asking her to administer an enema to help with his bowel movements:

The bathroom situation is horrible because the medication he's on causes constipation and his stomach bothers him and he needs enemas. He doesn't say, you know, "I need you to give me an enema," but he'll say, "I think I need a stool softener."

Helen explained that, although she has become accustomed to administering enemas to Walt (who, at age 80, has had PD for eight years), he continues to be indirect in asking for her help with this task. It is likely to be less face-threatening to make an indirect request for a stool softener than it is to make a direct request for an enema; thus, seeking support indirectly can allow a person to save face.

Similarly, by providing support subtly, a partner may help protect the PWP's face. Lisa, a 47 year-old PWP, emphasized that it is particularly important for support to be subtle when it occurs in a public arena. She noted that many of her PD symptoms (e.g., shaking, losing her train of thought mid-sentence) cause her embarrassment when they occur in public, and that her husband Joe can "save the day" by subtly providing assistance:

He's very good with how he does things. He won't say [in public], "Do you need help, Lisa?" If I get stuck in a conversation [in front of others], he'll jump right in and finish it where you don't even notice what he did. . . . We were at my uncle's funeral, and I got

really stuck, and he picked right up and started talking where nobody knew the difference.

In short, subtle support may help a PWP, like Lisa, save face during situations in which public self-presentation is a concern.

Having an outlet. As previously discussed, partners may, at times, feel overwhelmed or drained by the process of providing support to their PWP. Many participants noted the importance of the partner having an outlet (i.e., a hobby or activity unrelated to caring for the PWP). Doug, a 64 year-old partner, said that participating in his own activities helps him maintain his identity:

It's important to live my own life where you do things you like to do because otherwise, you get lost in a sea of not knowing who you are anymore because you're so concerned about the other person, and you're a lot stronger if you're living your own life with various things you do and define.

Furthermore, according to some participants, PWPs can help their partners by encouraging them to have this outlet. Deb, a 73 year-old PWP, said of her husband Larry: "I encourage him to go out the door. He likes to golf, and he's been going a couple times a week, so that's good." A partner, 38 year-old Kelly, expressed gratitude that her husband Ray (who was diagnosed with PD seven years ago in his early thirties) has started to recognize her need for a break from PD-related stressors:

Sometimes it's just like, "I need a glass of wine and I just don't even want to talk about [PD]; let's just find something fun to talk about," and that's a nice distraction. And he has even gotten to the point—in the last two years, we try and make it where me and [my best friend] will sometimes get a girls' night out. And sometimes, thank God, he will even

push me to [do this]: “You need time away; you need to just go relax.” He has changed on that. It used to be he would be like, “Why are you going out; what are you doing?” By no longer questioning Kelly’s need to spend time with a friend (and, in fact, encouraging her to do so), Ray is, in a sense, helping his wife manage the stress that can occur with the provision of support.

Using nonverbal cues. Another management strategy cited by participants was using nonverbal cues to frame support in a positive light. PWPs may be less likely to feel, for instance, as though their partner views them as a burden if support is communicated with nonverbal cues that convey patience. As previously mentioned, Martha, partner to 72 year-old PWP Donald, discussed the importance of managing one’s tone of voice when providing support. She advised,

Always use a gentle tone of voice, but that is personality, too. Donald’s easily hurt, and if I am frustrated and use an anxious tone of voice, he can pick up on it right away. You’re always a gentle, loving voice. [Otherwise] he bristles, and then he gets angry. His mood seems to follow my mood. It’s difficult, ‘cause there are days your back hurts, your foot hurts, you’re tired, you woke up with a headache, but you can’t let it show.

In sum, although support can, at times, be threatening to the PWP’s identity (e.g., by making him or her feel like a burden), this threat may be mitigated if support is communicated with nonverbal cues indicating patience, warmth, and caring.

Taking the other’s perspective. Finally, several participants said that they manage complications and costs of support by attempting to take their partner’s perspective. Imagining the situation from the other’s vantage point can be helpful in reframing challenges of support. Edna, a 73 year-old partner, said that, when she finds herself getting frustrated by her husband Eugene’s frequent requests for assistance, she tries to take his perspective: “It’s not easy for him.

Sometimes he'll keep hollering for help, again and again when I'm doing something—like I'll be brushing my teeth—and I remind myself, this is hard for him, too.”

In some cases, taking the other's perspective can be useful in managing the complication of having different preferences for coping with PD. For instance, 69 year-old PWP Anna explained that, although her tendency has always been to communicate less than her husband Doug would like, she has recently become more receptive to communicating about PD because she recognizes it is helpful to him. She described learning and using this management strategy of taking the other's perspective:

A couple weeks ago, we went to a blessing, which is like a wedding reception, and there was a little sermon, and [the officiant] said, “Well, my advice to couples is to look at things through the other person's eyes.” Well, that sounds like a real simple thing. It was put so simply that I thought, “I'm going to try that.” So the next day, I got up—I've been doing it ever since, and I can anticipate—it really works—I can anticipate more of what he needs, and that's made us get along better, I think. A lot of times, I'm a pretty independent person, and I can kind of go along and not communicate—you know, not talk about Parkinson's or whatever. I forget other people are needing to be listened to. So now, I think I'm not as self-centered. We've gotten along better since I looked right behind his glasses, just anticipate more of his needs, like “Okay, maybe he needs to talk now.”

In the process of trying to take Doug's perspective, Anna has become more open to coping with PD in ways that are supportive for him (even though they may differ from her own preferences).

Conclusion

Results of this study provide in-depth insight regarding the experience of coping with PD in a relational context. PD has far-reaching effects: In addition to the physical manifestations of the disease, PWPs encounter a multitude of psychosocial challenges. Partners are also likely to be dramatically affected, as is the couple's relationship. This examination of PD in a relational context allows for a detailed understanding of how PWPs and partners cope with the illness via the exchange of social support. Specifically, these results explicate ways that PWPs and partners reported communicating support to one another, complications and costs of supportive attempts, and strategies for managing these difficulties of support.

In the following chapter, conclusions from these results are reviewed and discussed. Although the strategies for managing costs and complications of support were reported by participants as effective, they are not all likely to always (or universally) be viewed this way. Thus, the next chapter addresses theoretical implications by presenting a normative/rhetorical model that proposes why and when (i.e., under what circumstances) these strategies are most likely to be perceived as effective in managing costs and complications of support in the PD context. Then, practical implications are outlined and, finally, limitations and directions for future research are discussed.

CHAPTER FIVE: DISCUSSION

Psychosocial research related to PD is relatively scarce (Brod, Mendelsohn, & Roberts, 1998). In particular, there is a lack of research examining coping with PD from a relational perspective (Hodgson, Garcia, & Tyndall, 2004; Schreurs, DeRidder, & Bensing, 2000). The current project addressed some of the gaps in the literature by (a) describing psychosocial stressors and relational issues experienced by PWPs and their partners, and (b) examining how PWPs and partners cope with these changes in a dyadic context via social support. Results clearly demonstrate that PWPs and partners encounter a host of difficulties that extend far beyond the physical manifestations of the disease. Furthermore, data reveal that PWPs and partners help one another in a number of important ways, but that social support is sometimes accompanied by costs and complications. Findings of this study also illuminate strategies that PWPs and partners consider to be effective in managing these costs and complications of support.

In this chapter, I begin by reviewing and discussing major conclusions of the study (as related to psychosocial challenges and social support), including how the results fit within the existing literature. In discussing the communication of support within couples coping with PD, I address theoretical implications by presenting a context-specific model of social support. In line with Goldsmith's (2004) normative/rhetorical approach, this model proposes why and when (i.e., under what circumstances) the specific strategies presented in the previous chapter are most likely to be perceived as effective in managing costs and complications of support. Then, practical implications of this research are explained. Finally, the chapter concludes with a discussion of limitations and directions for future research.

Before discussing conclusions about psychosocial challenges related to the PWP, partner, and relationship, it is important to note the highly overlapping nature of these experiences. When examining the content of the themes affecting the PWP, partner, and relationship, it is clear that coping in a relational context inevitably means that the experience of one party affects the other, along with the relationship that they share. If, for example, the PWP withdraws from communication due to the communication-debilitating effects of the disease, this change is likely to dramatically affect the partner (who may become lonely as a result of not having the PWP to talk to), as well as the relationship (e.g., relational closeness may decrease). As mentioned in the previous chapter, Figure 1 summarizes the psychosocial issues affecting the PWP, partner, and their relationship—with arrows representing the fact that PWP challenges, partner challenges, and relational issues all influence one another.

Psychosocial Challenges Experienced by PWPs

Consistent with previous work deeming chronic illness as a major life disruption for the patient (e.g., Bury, 1982; Corbin & Strauss, 1987), participants reported that PD affects the PWP in a multitude of significant ways. Data from the current study reveal that, in addition to the physical symptoms of PD, PWPs may face psychosocial issues related to having to give up or struggle with certain leisure activities, having difficulty fulfilling previous roles, being treated as helpless or ill, experiencing communication-debilitating symptoms, having concerns about public self-presentation, experiencing changes in social life or sociability, being unable to predict their daily well-being, and feeling uncertain about their disease progression and the future. As discussed in the following subsections, these results provide compelling evidence that PD is an illness that is both highly identity-threatening and uncertainty-inducing for PWPs.

PD as an Extraordinarily Identity-Threatening Illness for PWP

Many of the psychosocial challenges for PWPs that participants described have negative implications for a PWP's identity and provide evidence for the highly identity-threatening nature of PD. Specifically, the themes of having to give up or struggle with certain leisure activities, having difficulty fulfilling previous roles, being treated as helpless or ill, having concerns about public self-presentation, experiencing communication-debilitating symptoms, and undergoing changes in social life or sociability are especially relevant to identity issues. A discussion of each of these psychosocial challenges in relation to identity elucidates issues that make PD extraordinarily threatening to the identities of individuals afflicted with it.

To begin, because people develop and maintain their identity, in part, through actions and appraisals (Charmaz, 1987), no longer being able to engage in valued activities and previous roles can be devastating. Losing the ability to participate in cherished hobbies as a result of the physical effects of the disease may threaten a PWP's self-concept as well as change the way others think of him or her. Participants in this study reported PWPs having to withdraw from, or struggle with, hobbies as varied as horseback riding, traveling, playing musical instruments, reading, riding motorcycles, and playing sports. Similarly, having difficulty fulfilling non-leisure tasks or roles can also negatively impact a PWP's identity, such as when a PWP who used to pride himself on being "Mr. Fix-It" can no longer complete home repairs because of diminished fine motor skills and decreased concentration. Additional examples from this project's data further demonstrate ways in which having to withdraw from previous roles or tasks due to PD can have detrimental effects on a PWP's identity. For instance, no longer being able to maintain employment may lead a PWP to suffer from a reduced sense of self-worth, whereas having to give up driving can shatter a PWP's sense of freedom and identity as an independent individual.

Like the psychosocial challenges of PWPs losing the ability to fulfill leisure and non-leisure roles and tasks, the theme of being treated as helpless or ill by others has significant identity implications. During social interaction, people's identities are constructed and managed over time (Hewitt, 1993; Howard, 2000; Tracy, 2002). One way that this occurs is via altercasting, which refers to the process of people putting others in roles (i.e., enacting their perception of others' identities) through communication (Hewitt; Tracy; E. A. Weinstein & Deutschberger, 1963). Results of this study indicate that, in the PD context, altercasting the PWP as helpless or ill can take the form of doting on or making concessions for the PWP; some PWPs said that when others provide "excessive" help, they take it as a sign that people perceive them as incapable. When PWPs are altercast in ways that are inconsistent with their desired image, they may begin to internalize (and perhaps even eventually enact) the role that others have "put upon" them. For example, someone who is continually helped may, over time, become unable or unmotivated to complete tasks on his or her own.

Alternatively, PWPs may respond to being altercast as helpless or ill by trying to resist and renegotiate this identity. As detailed in the previous chapter, for instance, Jack (a 47 year-old PWP) objected to a friend altercasting him as "feeble" when she assumed he might have trouble taking off his shoes before entering her home:

My brother and I stopped in to see [a friend] because we happened to be in the neighborhood, and we hadn't seen their new house. My brother said, "Could we get a quick tour?" and she said yeah. He said, "Should we take our shoes off?" She said, "Well, you don't really have to. Jack, I know that might be really difficult for you." I was like, "No, it's not [difficult]. I have *no* trouble." I stood there on one leg and took my shoes off

just to show her I could do it. And then I got a little wobbly. [laughs] But, I was like, “I’ve got it; I did it. There you go!”

In Jack’s mind, his friend’s implication that he might not be able to remove his own shoes cast him as “Jack with Parkinson’s” rather than his desired identity as “just Jack;” therefore, he was eager to demonstrate that her worry was unfounded. In short, being treated as helpless or ill can be threatening to a PWP’s identity by leading to concerns that others view him or her as somehow different (e.g., less capable) as a result of having PD. Some PWPs, like Jack, may respond to this form of altercasting by trying to discredit identity implications that they perceive as undesirable or threatening.

Another psychosocial challenge that emerged as a theme for PWPs and that has relevance to identity issues is having concerns regarding public self-presentation. Not only can others impact a person’s identity during social interaction via altercasting (Hewitt, 1993; Tracy, 2002; E. A. Weinstein & Deutschberger, 1963), an individual also plays a role in forming and externalizing his or her own identity through the process of self-presentation. Self-presentation refers to the formation and management of a person’s own identity (Goffman, 1959; Hewitt; Leary, 1995; K. A. Martin, Leary, & Rejeski, 2000; Tracy). Results of this project demonstrate that the effects of PD (e.g., shaking, imbalance, and a lack of coordination) can severely compromise PWPs’ ability to present themselves in public in a manner that is in line with their desired image. Consistent with previous research that found shame as a common occurrence among PWPs (Nijhof, 1995), findings from the current study reveal that PWPs often feel embarrassed or ashamed when they are unable to hide the physical symptoms of PD, such as when symptoms interfere with the ability to perform tasks. PWPs reported self-presentational concerns related to having difficulty engaging a variety of activities including participating in

physically-oriented hobbies, writing a check, and dining in public. Self-presentational concerns may be especially salient when a PWP struggles to perform an activity that has been a central part of his or her identity for years. Greg (a long-time sports enthusiast and player), for example, became “greatly embarrassed” when PD interfered with his ability to throw a ball back to the pitcher while serving as an umpire for his son’s team. PWPs sometimes feel that they are losing control of not only their physical selves but also their ability to present a desired image of themselves.

Results demonstrate that another source of self-presentational concerns in the PD context is having communication-debilitation symptoms. Because communication is central to presenting and negotiating one’s identity (Howard, 2000; Tracy, 2002), it stands to reason that PD (and other communication-debilitating illnesses) would be particularly threatening to one’s identity. Consistent with other research that has established a deterioration in communication abilities as a common occurrence among PWPs (e.g., E. Berg, Björnram, Hartelius, Laakso, & Johnels, 2003; Murray, 2000), participants in the current study often reported that the PWP’s ability to communicate had been compromised in multiple ways, including memory and concentration, volume, clarity, nonverbal expressiveness, and writing. These communicative challenges can incite anxiety related to identity issues. Some PWPs, for example, recalled feeling embarrassed when losing their train of thought mid-sentence and worried about when this symptom of PD would arise next; they feared others would think they were unintelligent or socially incompetent. Sadly, previous research indicates that such concerns (i.e., about how communication-debilitating symptoms can lead to others’ negative evaluations of PWPs) are warranted: Compared to healthy control participants, PWPs have been “rated as sounding significantly less happy, friendly, interested, and involved” by others based on recorded speech samples (Jaywant

& Pell, 2010, p. 54). Communication-debilitating symptoms can dramatically interfere with PWP's ability to present themselves in desired ways, and this has implications for the way they are viewed by themselves and others.

Finally, identity issues are also relevant to the theme of PWP's experiencing changes in social life or sociability. Results demonstrate that PWP's often experience a loss of social life. In some cases, this is due to no longer being able to participate in the same social activities because of PD (e.g., it may become difficult or impractical to play bridge with a severe tremor). In other cases, PWP's withdraw from social interaction due to the aforementioned issue of having self-presentational concerns. Some PWP's attempt to hide their symptoms (e.g., by holding their hands together to conceal a tremor, or talking less to hide communication-debilitating symptoms); when symptoms become difficult or impossible to mask, they may avoid socializing whenever possible. This social isolation can affect a PWP's identity by making him or her feel abnormal or like an outcast.

In sum, one major contribution of the current project is that it establishes PD as an extraordinarily identity-threatening illness. Although other studies about PD have explored how the disease affects particular aspects of identity, such as womanhood (Fleming, Tolson, & Schartau, 2004), examining the culmination of factors that contribute to identity shifts for PWP's has not been a salient topic in the literature. Identity has, however, been more extensively studied in relation to chronic illness in general. Based on intensive interviews with people with chronic illness, Charmaz concluded, "A fundamental form of . . . suffering is the loss of self in chronically ill persons who observe their former self-images crumbling away without the simultaneous development of equally valued new ones" (1983, p. 168). Indeed, in the PD context, this "crumbling away" happens in a variety of ways (e.g., through the loss of cherished

activities and a diminished ability to communicate). As demonstrated by the current project, it is important to consider the effects of specific illness conditions on identity; the unique manifestations of a particular illness can change the way identity is impacted. For example, due to the visibility and embarrassment associated with some possible effects of PD (e.g., falling, shaking, drooling, slurring one's speech), a PWP faces very different identity challenges than a person with an invisible illness (e.g., heart disease). Many of the themes that emerged as findings in the current project have implications for how the disease can affect the PWP's identity and offer evidence for the conclusion that PD is likely to be highly identity-threatening.

PD as an Uncertainty-Inducing Illness for PWPs

Results of this study not only further our understanding of the ways that PD can threaten a PWP's identity, but also lend support to a small body of past research acknowledging that PD is an illness characterized by uncertainty. Uncertainty has been widely recognized as a common feature in the experience of illness (e.g., Babrow, Kasch, & Ford, 1998; Brashers et al., 2003; Mishel, 1988, 1990). Although uncertainty has not been extensively explored in the PD context, a small number of past studies have illuminated some sources of PWPs' uncertainty. Dakof and Medelsohn (1986), for instance, noted that PWPs experience uncertainty about when symptoms will occur as well as about when the disease will worsen. Consistent with these findings, results from the current project indicate that two salient issues that PWPs encounter as a result of the disease are being unable to predict their daily well-being and feeling uncertain about their disease progression and the future.

Regarding uncertainty about their daily well-being, many PWPs spoke of the frustration of not knowing in advance whether it was going to be a "good day or a bad day." PWPs sometimes go through a period in which their symptoms are reasonably well-controlled by

medication, only to have this unexpectedly interrupted by a dramatic increase in PD symptoms (perhaps indicating a changing response to medication; NINDS, 2006a). This unpredictability about daily well-being can make it difficult to make plans and sometimes leads to having to cancel prior commitments. Regarding uncertainty about longer-term PD progression and the future, PWPs expressed questions about how quickly the disease would progress, whether it would eventually lead to their death, and what their future care would entail. Knowing that PD is a progressive disease, but not knowing exactly how and at what rate progression will occur, is a significant source of uncertainty for PWPs. In sum, these results clearly demonstrate that experiencing uncertainty about daily well-being and having questions about longer-term disease progression are salient psychosocial challenges for PWPs.

Although the current project did not focus in-depth on PWPs' *response* to uncertainty, findings suggest that accepting uncertainty as a way of life may be an adaptive response (see also Brashers, 2001; Mishel, 1990). Living with chronic uncertainty sometimes involves a PWP accepting that he or she will inevitably have "bad days" and that it may not always be possible to predict when those days will occur. Deb, for instance, said that she has learned that a PWP (like herself) should, "Enjoy everyday, and whatever you can do, just do it, because you never know what the next day's going to be." Ironically, accepting uncertainty as a part of life seems to entail coming to terms with the certainty of *not* always being able to know what to expect. This process can even involve the paradoxical idea of making plans in advance for handling an unexpected disruption in plans. Some PWPs in the current study, for example, described telling people that they have PD, in part, so that others would understand if they were to need to cancel an engagement at the last minute. Accepting chronic uncertainty as a part of life may be an

important coping mechanism for PWPs considering the vast amount of uncertainty that PD can incite about daily well-being as well as the longer-term future.

Psychosocial Challenges Experienced by Partners

In addition to yielding conclusions about PWPs, results of this study extend our understanding of partners' experience of PD. Previous research regarding partners of PWPs has focused almost entirely on caregiving (e.g., Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; E. Miller, Berrios, & Politynska, 1996; Thommessen et al., 2002). Findings from the current project, however, demonstrate that partners experience a variety of psychosocial issues as a result of PD (only some of which directly relate to caregiving). Themes from the data indicate that partners face challenges related to being unable to “rescue” the PWP from the challenges of PD, being the recipient of the PWP's frustration, getting impatient with the PWP, shouldering increased responsibility, missing the PWP's pre-PD identity, being confronted with the prospect of losing the PWP, losing valued activities, having the PWP withdraw from communication, feeling housebound due to the PWP's dependence, being unable to predict the PWP's daily well-being, and experiencing uncertainty about future caregiving and disease progression. Thus, an important contribution of this project is that it provides a more complete conceptualization of partners' experience than was previously available in the research literature—acknowledging that a diagnosis of PD entails a complex, multidimensional set of challenges not only for the PWP but for the partner as well. In the following subsections, partners' experiences relating to caregiving and non-caregiving challenges are outlined.

Partners' Experience of Caregiving

Several of the themes that emerged as psychosocial challenges for partners are directly tied to caregiving. A majority of partners reported, for example, that they had taken on more

responsibility as result of their PWP's illness. Among the additional tasks and roles mentioned were becoming the sole breadwinner, managing the couple's finances, taking over the driving, and doing the majority of household chores. Consistent with previous literature in the PD context linking caregiving to detrimental effects on the caregiver (e.g., E. Miller et al., 1996; Thommessen et al., 2002), partners cited this increased responsibility as a highly stressful consequence of PD; they described feeling "overwhelmed" or even "trapped." Some partners reported feeling like the work of maintaining a household and taking care of a family was now entirely on them, rather than shared by the PWP. As detailed in the previous chapter, Pam (age 51) described the tremendous pressure she has felt since her husband was diagnosed with PD:

I think the spouse, whether it's the wife or the husband, in this case, the wife, feels like okay, I've got to stay healthy. I've got three kids to tend to. And then he'll come back with a comment: "I'm not dead yet." Yeah, I know, but I guess that's where it's changed. I don't want to put any more burden on him or make him feel stressed. When the stress level rises, the symptoms really peak, or you can see them more and hear it in his voice and in his walking.

Thus, for some partners, caregiving entails trying to independently handle family responsibilities in order to minimize stress for the PWP—and this transfer in responsibilities can create considerable pressure for partners.

Another psychosocial challenge relevant to partners' experience of caregiving is the partner struggling to maintain his or her patience with the PWP. A common source of impatience mentioned by partners is that, because PD is a movement disorder, PWPs often progress slowly when completing a physical task. Many partners reported getting frustrated with their PWP's slow pace and then feeling guilty about their impatience. Judith, for example, said of her

husband, 89 year-old PWP Lawrence, “Sometimes I tell him to hurry, and I never, never should do that. He can’t hurry.” Maintaining patience can be especially difficult in light of the fact that partners may already be in a negative emotional state (e.g., due to the stress of shouldering additional responsibility).

In addition to caregiving challenges related to increased responsibility and maintaining patience with the PWP, partners in the current project said that being housebound due to the PWP’s dependency was a problematic issue. This challenge tends to affect partners whose PWP have more advanced cases of the disease; such partners often cited concerns about not wanting to leave their PWP unattended for fear that he or she might require care or experience an emergency (e.g., falling or choking due to the effects of PD). Not feeling comfortable leaving the PWP alone leads to practical concerns about how the partner will handle necessary outings such as grocery shopping. Although a number of partners said that they take their PWP with them on errands to avoid the issue of leaving him or her unattended, others said that having the PWP come with them everywhere is not a good alternative because it is too physically taxing for the PWP. As a result, some partners minimize leaving the house as much as possible and, when they do need to go somewhere, are careful to return quickly. Feeling the need to constantly stay home to take care of their PWP is not only challenging for partners from the perspective of needing to leave the house for practical reasons (e.g., grocery shopping), but can also lead to a dramatic loss in partners’ social life (which past research has acknowledged as a problem among caregivers in the PD context; O’Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006; Thommessen et al., 2002).

Finally, psychosocial challenges related to caregiving can also stem from uncertainty. As previously discussed, uncertainty is a salient aspect of the experience of illness for patients

(Babrow et al., 1998; Brashers et al., 2003; Mishel, 1988, 1990). Less commonly, the uncertainty of a patient's loved ones has been documented (e.g., Donovan-Kicken & Bute, 2008; Goldsmith, 2009; Stone & Jones, 2009). The uncertainty of partners has not been examined in detail in the specific context of PD. In the current project, findings about partners' uncertainty mirror PWP's uncertainty; partners expressed uncertainty related to being unable to predict the PWP's daily well-being as well as regarding future disease progression. These forms of uncertainty are not always directly (or solely) related to caregiving (e.g., a partner's questions about disease progression may be a result of wondering not about caregiving, but how PD will affect the couple's plans to travel during their retirement). When these forms of uncertainty do relate to caregiving though, they can include constant concerns about the PWP experiencing a traumatic injury or event such as falling or choking due to the effects of PD, or the longer-term issue of whether or not the partner will be able to continue to care for the PWP in years to come.

Beyond Caregiving: Partners' Experience of PD as a Complex Set of Challenges

Although providing care for the PWP can be an extremely salient part of the experience of PD for a partner, findings from the current research suggest that caregiving does not represent the totality of psychosocial challenges that partners encounter; partners' lives are often also dramatically disrupted by PD issues not directly related to providing care for the PWP. Even apart from caregiving-related issues, partners may experience deep sorrow both in regards to what the PWP is going through and with respect to their own losses. Consistent with the past research finding that partners' biggest challenge is often watching their PWP struggle (Habermann, 2000), many partners discussed feeling great sadness at witnessing their PWP decline in health, as well as considerable frustration at not being able to "rescue" him or her from this deterioration. Several partners talked about this inability to alleviate their PWP's struggles as

a threat to their own identity (e.g., as a “fixer,” “protector,” or “rescuer”), suggesting that PD is identity-threatening not only to PWPs but also partners. Further evidence of the identity-threatening nature of PD for partners is that it often becomes impractical to continue valued activities that they previously shared with their PWP (e.g., dancing, traveling) because the PWP can no longer participate. As previously mentioned in regards to PWPs, one way that people develop and maintain their identity is through the hobbies they participate in; therefore, having to give up valued leisure activities can have devastating identity implications.

Other psychosocial challenges experienced by partners also relate to sadness and loss. Some partners discussed missing the PWP’s pre-illness identity. In particular, the common occurrence of PWPs withdrawing from communication can be devastating to partners who may feel that they have, in a sense, lost their long-time companion. This phenomenon of ambiguous loss (i.e., having a person physically present but psychologically distant) is a frequent phenomenon among loved ones of other neurologically-debilitating illnesses like Alzheimer’s disease (Boss, 1999). Based on results of the current project, ambiguous loss in the PD context seems to be limited to partners whose PWPs are in highly advanced stages of the disease—a logical association considering those PWPs are the ones most likely to demonstrate severe symptoms, inducing identity changes and communication withdrawal. Partners may also feel anticipatory loss at the idea of their PWP dying as a result of PD. For partners, being confronted with the possibility of losing their spouse can create feelings of grief, as can missing the partner’s pre-illness identity or style of communication. In sum, unlike past research on partners that has focused almost exclusively on caregiving, the current project recognizes that a partner’s experience of PD encompasses a complex, multidimensional set of challenges.

Relational Issues

A final set of psychosocial challenges examined in this project has to do with the relationship between the PWP and partner. Although research has demonstrated that, in general, chronic illness can invoke many issues for a couple (R. F. Lyons, Sullivan, Ritvo, & Coyne, 1995), few studies have explicitly focused on how the relationship between a PWP and partner is affected by PD. Results from the current project indicate that PD can have dramatic effects on the patient-partner relationship, even though most participants reported that PD had not decreased their overall relational closeness. Relational issues mentioned by participants include shifting relational roles, experiencing changes in sexual intimacy, facing financial stress, engaging in fewer leisure and social activities together, and experiencing uncertainty about their relationship. A contribution of the current research is that it offers compelling evidence that PD is a relationally-disruptive experience, as discussed below.

Considering the detrimental psychosocial issues that PD ignites in both the PWP and the partner, the current project's finding regarding whether PD changes couples' overall level of relational closeness may, at first, seem somewhat surprising: The majority of participants said either that there has been no change in their relational closeness or that PD has made them closer. This research suggests that already having a long relationship history at the time of the PD diagnosis may make it less likely that PD will negatively affect a couple's closeness. A partner named Bonnie, for example, cited the long-term, stable relationship she has with Ron (her husband of 44 years) as the reason that PD has not changed their closeness: "When you've been married as long as we have, it takes a lot to shake things up." Many PWPs and partners echoed Bonnie's sentiment; most participants in the sample had a lengthy relationship history (the average was 38 years) and, in the majority of cases, the PWP was not diagnosed until many years

into their relationship. These factors offer a possible explanation for why the majority of couples reported no change in overall relational closeness, or even reported becoming closer, as a result of PD. It is also possible, of course, that the couples who adjust the worst to PD were not captured in this sample because they do not stay together long after diagnosis. Some participants, however, did say that they are less close as a result of PD, or that they had experienced a past period of decreased closeness due to PD but had worked through it. The participants who did report current or past decreases in relational closeness due to PD mentioned having a brief relationship history (e.g., only being married three years at the time of diagnosis) or experiencing high levels of uncertainty about the relationship (which has generally been linked to worse marital quality; e.g., see Knobloch, 2008).

Previous research on the effects of chronic illness on relationships is mixed, with several studies reporting some positive relational consequences in the PD context (Habermann, 2000; Hodgson et al., 2004) and other illness contexts (Bute, Donovan-Kicken, & Martins, 2007). Yet R. E. Carter and Carter (1994) found that, overall, PD was related to poor marital adjustment. In addition, past literature related to PD has described relational problems due to a loss of shared activities (Habermann) or changes in a couple's sexual relationship (R. G. Brown, Jahanshahi, Quinn, & Marsden, 1990). These problems (and others) also emerged as salient themes in the current project—suggesting that, even though the majority of participants do not consider themselves to be less relationally *close* to their partners because of PD, the illness has invoked a number of relational issues. That is, results indicate that PD is a relationally-disruptive illness that often entails a number of challenges for a couple's relationship, but also that facing these challenges does not necessarily diminish closeness. (In fact, most of the participants who reported *increased* relational closeness attributed this positive change to the process of working

together to face PD-related problems.) As previously mentioned, some of the relational issues that emerged as salient in the current project were experiencing changes in sexual intimacy, facing financial stress, engaging in fewer leisure and social activities together, and experiencing uncertainty about their relationship.

Lastly, a central way that PD disrupts relationships is that it can often lead to shifts in relational roles for PWPs and partners. Many participants said, for example, that their relationship feels, at times, more like a “caregiver and care recipient dynamic [than like a marriage].” As discussed earlier in this chapter, the experience of PD can individually threaten the identities of the PWP and the partner. This can also happen at the relational level; by enacting caregiver/patient roles, a couple may lose their pre-illness identity (e.g., as romantic partners). Some participants spoke of the importance of the partner enacting the caregiver role as needed, but also acting like a husband or wife (i.e., a romantic partner) at other times. In explaining this, 59 year-old PWP Tina said, “I don’t want to be married to just a caregiver.” Other participants said they dislike the idea of one person in the dyad being considered the “caregiver” because of what it implies about the relationship (i.e., that one person is doing all of the care provision). Lisa, a 47 year-old PWP, described being shocked and offended when her doctor gave her husband a video to watch about him “being a caregiver” because it made her feel like a burden. In many couples, both people take care of one another, thereby blurring the roles of support provider and support recipient (Goldsmith, 2004); this is especially true when both people in the dyad have health problems. The finding that several participants objected to the label *caregiver* echoes results from a study by Habermann (2000) in which some partners resisted the term *caregiver* and described the support they provided as a natural part of marriage. In sum, PD is

relationally-disruptive for a number of reasons, including that it often necessitates shifts in relational roles.

Communication of Social Support Within Couples Coping with PD

The current project aimed to not only provide a detailed understanding of psychosocial challenges and relational issues faced by PWP and partners, it also sought to extend the literature on how couples cope with these challenges in a relational context via social support. Several researchers have commented on the lack of work examining social support in PD; for instance, Schreurs et al. (2000) said, “[I]n light of the extensive literature on adaptation processes to chronic disease . . . the paucity of studies on coping and social support in PD is striking” (p. 109). The present research makes important contributions to this understudied topic by describing ways that PWP and partners communicate support to one another, costs and complications of support, and strategies for effectively managing these challenges of support. These findings, along with their theoretical implications for a normative/rhetorical model of social support in the PD context, are summarized and discussed below.

Ways of Communicating Support

Participants described five main ways of communicating support to one another. First, they reported assisting one another with the activities of daily living. Consistent with prior research on couples coping with chronic illness (Corbin & Strauss, 1988), PWP and partners discussed managing *illness-related work* (e.g., organizing PD medications) and *everyday life work* (e.g., completing household chores). Typically, the partner takes on additional responsibilities due to the PWP’s physical restrictions; however, a number of couples were quick to point out that they have a communal approach to accomplishing the activities of daily living that entails each person helping the other. This finding is in line with Goldsmith’s (2004)

assertion that it is not always easy to decipher who is the support provider and who is the support recipient (see also R. F. Lyons, Mickelson, Sullivan, & Coyne, 1998). Second, social support in this context can take the form of the partner helping the PWP stay active through joint activities. Participants discussed, for example, playing Scrabble in an attempt to maintain the PWP's mental sharpness or exercising together to keep the PWP physically active. The distinction of the partner doing an activity *with*, rather than *for*, the PWP is indicative of a communal approach to coping (see R. F. Lyons et al.) and may yield relational benefits in terms of engaging in a satisfying behavior together. Third, participants described providing emotional support to one another. This type of support seems to be especially important for both partners and PWPs around the time of diagnosis, when each member of the dyad is likely to experience a range of negative emotions. Fourth, participants said that they exchange informational support within the dyad. This can entail both parties sharing PD-related information from media sources. Other frequently cited ways of communicating informational support were for partners to give advice or accompany the PWP to medical appointments to help with the provision, gathering, retention, and interpretation of information. Finally, some participants discussed encouraging perspective shifts as a way of communicating social support (such as when a partner encourages a PWP to accept his or her physical limitations). In sum, social support is communicated in a variety of ways in the PD context, and is not restricted to the partner always serving as the provider of support with the PWP in the recipient role.

Costs and Complications of Support

Although a number of researchers (e.g., Albrecht & Adelman, 1987; Coyne, Ellard, & Smith, 1990; Lehman, Ellard, & Wortman, 1986; Silver, Wortman, & Crofton, 1990) have noted that the exchange of social support can entail difficulties, Goldsmith's (2004) normative/

rhetorical approach goes a step further by taking a multiple goals perspective to explain *why* these challenges occur. Multiple goals perspectives assume that, during an interaction, participants are working to accomplish several purposes; for instance, people are not only engaging in a task, but also attending to goals related to establishing or maintaining a relationship and protecting their own and others' desired identities (Clark & Delia, 1979; O'Keefe, 1988; O'Keefe & Shepherd, 1987). According to Goldsmith's normative/rhetorical approach, social support is effective to the extent that task, identity, and relational goals are balanced. When these goals collide, dilemmas (i.e., social challenges) of support occur.

The current project illuminates several challenges of social support. Specifically, participants reported that partners' differing approaches to coping can make support difficult, support can be threatening to the PWP's identity as independent/capable, support can be interpreted as controlling, support can place an unwanted emphasis on the disease, support can bring concerns about burdening the other, support can lead to dependency, and support can be draining. As discussed below, these costs and complications can result from the difficulty of balancing multiple goals and sometimes lead to dilemmas.

To begin, this research demonstrates that a problematic reality of dealing with PD in a relational context is that PWPs and partners sometimes have differing approaches to coping, which can make social support challenging. One partner, for example, may prefer to discuss the disease frequently whereas the other wants to talk about it only occasionally, or one person may wish to find (and share) as much information as possible while the other seeks to avoid information. Past research has produced mixed results on whether it is important that partners' coping styles are congruent (C. A. Berg & Upchurch, 2007). Findings from the current study, however, suggest that incongruent approaches to coping can be highly detrimental to the

communication of social support. For instance, if one person in the dyad wants to talk about PD and the other refuses, these discordant preferences can lead to mutual frustration with both people facing the dilemma of either adhering to their own preferred way of coping (and, in effect, letting down their partner) or satisfying their partner's desires (at the cost of giving up their own goals).

Other dilemmas of support evident in the results of this study stem from trying to balance competing task and identity goals. Partners may wish to accomplish a task goal of communicating support (e.g., by providing tangible assistance), but not know how to do so without threatening the PWP's desired identity (e.g., as independent and capable). Similarly, results indicate that a PWP may need tangible support, but hesitate to ask for it because he or she dislikes the identity implications that can accompany such help (e.g., that he or she is ill or helpless). Moreover, findings suggest that a partner may struggle to mesh the task goal of providing advice with the identity goal of not coming across as bossy or as a "nag." All of these situations exemplify circumstances in which people encounter competing goals. Each one presents a similar dilemma: Should the partner (or PWP) provide (or seek) support and risk the negative identity implications? While that option may be unappealing, so too is the alternative of opting not to seek/provide support (and, in effect, missing out on an opportunity to get or give help that may be sorely needed). As outlined by past research, these dilemmas exist as a result of the fact that supportive attempts can have multiple possible meanings (e.g., advice can be viewed as caring or as an unwanted intrusion that threatens the recipient's identity; Goldsmith & Fitch, 1997; Goldsmith, Lindholm, & Bute, 2006). The current project demonstrates that PWPs and partners help one another in important ways by communicating support, but that this support is not without complications and costs.

Strategies for Effectively Managing Costs and Complications of Support

A critical part of this project's aim to extend our understanding of social support within couples coping with PD was to not only delineate costs and complications, but also to examine what strategies participants consider to be effective in managing these challenges of support. PWPs and partners described a number of strategies that they perceive as effective in managing complications and costs of support: framing partners as equals, relinquishing control, having the partner follow the PWP's lead, using humor, seeking/providing support indirectly or subtly, having an outlet, using nonverbal cues, and taking the other's perspective. There is a need for research that goes beyond typologies to also explore *why* certain strategies are viewed as effective or helpful (Goldsmith, 1992, 2004; Goldsmith & Fitch, 1997); therefore, based on data from this project, I propose *why* and *when* (i.e., under what circumstances) these strategies are likely to be perceived as effective within couples coping with PD. I discuss these strategies in more detail in the following section by presenting a normative/rhetorical model of social support that is specific to the PD context.

Theoretical Implications: Developing a Normative/Rhetorical Model of Social Support in the PD Context

Findings of the current project have important theoretical implications for Goldsmith's (2004) normative/rhetorical approach to studying social support. Most notably, results inform the development of a normative/rhetorical model of support for couples coping with PD. In the following paragraphs, I outline this model (which explains why and when certain strategies are likely to be effective in managing costs and complications of support in the PD context). First though, it is worth briefly revisiting an earlier discussion (from the second chapter) about the value of illness-specific models of support. Goldsmith noted that, because support is enacted and

interpreted differently depending on the context, it is imperative to create models of support that attend to the particularities of a certain illness. Examining the psychosocial challenges and relational issues of PWPs and partners was a valuable first step toward developing a normative/rhetorical model of social support for couples coping with PD because it provided in-depth insight into the unique psychosocial aspects of this specific illness. Completing a detailed analysis of an illness context enables a better understanding of the meanings that members of this population might ascribe to supportive attempts. For example, the study's conclusion that PD is a highly identity-threatening illness for PWPs helps frame our understanding of reasons *why* PWPs often perceive an unsolicited support attempt as unhelpful (e.g., one reason is that the PWP may feel that unsolicited assistance is an identity-threatening sign that others see him or her as helpless or ill). In contrast (and lending support to the importance of illness-specific models) is the fact that patients in some other illness contexts, such as transplantation, tend to actually prefer unsolicited support (Scott, Martin, Stone, & Brashers, 2011). In short, developing a normative/rhetorical model of social support requires an understanding of the illness factors that could affect the exchange of support and how it is perceived; thus, the current project's in-depth exploration of psychosocial challenges adds strength to the model outlined below.

Data from the current project support the normative/rhetorical perspective that people are trying to satisfy multiple goals simultaneously (see also Clark & Delia, 1979; O'Keefe, 1988; O'Keefe & Shepherd, 1987), and that there are more and less effective ways to manage the costs and complications that can arise from trying to balance competing demands (Goldsmith, 2004). By proposing *why* and *when* the eight strategies presented in the previous chapter are likely to be helpful in managing costs and complications of support (as summarized in Table 4), I illuminate

recommendations about support that are grounded in the communicative situation and relevant to PD specifically.

First, *framing partners as equals* when offering or providing support could, for example, entail a partner saying, “You know, sweetheart, you’ve been so busy; you’ve been doing so much in the yard lately. Would you mind if I just did the checkbook this month?” A reason why this strategy is likely to be helpful is that it minimizes the threat to the PWP’s identity because the PWP is altercast as equal when the partner offers/provides support. Also, it minimizes the threat to the relationship because the partner communicates in a manner that emphasizes interdependence and relational equity. An example of a circumstance in which this strategy is likely to be helpful is when the PWP requires tangible support because he or she can no longer fulfill previous roles. The diminished capacity makes a threat to identity particularly salient; therefore, a strategy that provides instrumental help without highlighting the diminished capacity is particularly well suited for the complications of the situation.

Second, the strategy of *relinquishing control* might involve the partner giving the PWP freedom to “come up with his [or her] own plan” of PD management rather than constantly providing unwanted advice (which is often interpreted as nagging). A reason why this strategy is often considered effective is that it can reduce relational strain that may occur when one or both partners perceive a power struggle (e.g., doing things “my way” versus “your way”). In addition, by giving up control, the support provider is freed from being labeled as a “nag” and the support recipient is empowered by being altercast as independent and capable. An example of when this strategy is likely to be effective is a situation in which the partner has repeatedly offered help and the PWP does not want it (e.g., when the partner communicates advice and the PWP opts not to follow it).

Third, *having the partner follow the PWP's lead* may take the form of the partner not providing support unless the PWP asks for it (or not talking about PD unless the PWP brings it up). This strategy can be effective because it alleviates the possibility of the partner offering/providing unwanted help that may be identity-threatening (or engaging in communication about PD when the PWP does not want to). There are several (sometimes overlapping) possible situations that exemplify when this strategy is most likely to be helpful. To begin, when independence is especially important to the PWP (such that offers to help with routine tasks would likely constitute a significant identity threat), following the PWP's lead can help protect the PWP's identity. Similarly, this strategy is likely to be effective when the PWP prefers not to talk about the illness because he or she considers communication about PD an unwanted reminder of the disease. Following the PWP's lead tends to work best when the PWP is motivated and capable in terms of completing some tasks on his or her own; conversely, it would not be an effective strategy to use when the PWP has an advanced case of PD and requires constant care. Finally, this strategy is optimal only if the partner knows that the PWP will in fact ask for help when it is needed (or bring up the topic of PD when he/she wants to talk about it); otherwise, there is the risk of the PWP not getting the support he or she needs.

Fourth, *using humor* was also reported by participants as a strategy that can be effective in managing costs and complications of support. An example of this strategy is "teasing" a PWP about veering into other lanes while driving rather than advising the PWP, in a non-joking manner, to give up driving. Results suggest that, if it is in line with a couple's typical communication repertoire, using humor may help a couple to feel more comfortable when talking about PD. Also, advice given in a joking manner may make a person feel less intruded upon because it can be "brushed off" as a joke. Using humor as a strategy is likely to be

perceived as effective only if the relationship dictates it (i.e., when it is consistent with a couple's preferred style of communication). Humor would be considered conventionally ineffective, however, if the PWP really needed some form of support or direction (e.g., the PWP had become a dangerous driver), but the humor allowed the PWP and partner to avoid the issue.

Fifth, data from this study revealed that *seeking/providing support indirectly or subtly* is often perceived by PWPs and partners as an effective way of managing costs and complications of support. Partners may, for example, subtly place their hand over the PWP's to help conceal a tremor if they know the PWP is self-conscious about this symptom becoming visible. This strategy is likely helpful because being indirect or subtle can make asking for or receiving support less face-threatening. Being subtle or indirect may be an especially successful strategy for support communicated in public, or when the nature of the support is particularly identity-threatening.

Sixth, *having an outlet* (e.g., playing golf or getting together with friends) can help dissipate the stress a partner often feels related to PD by providing an opportunity for distraction, enjoyment, or cathartic release of emotions. In addition, having an outlet can help the partner maintain aspects of his or her pre-PD (and pre-caregiver) identity. This strategy is likely to be particularly helpful when the partner has shouldered a considerable amount of additional responsibility as a result of PD (as is typically the case). In addition, if the partner's identity has been threatened by PD (e.g., as a result of becoming entrenched in caregiving tasks, or due to giving up social activity), this strategy can be especially successful.

Seventh, *using nonverbal cues* can also be effective in managing costs and complications of support because nonverbal communication allows partners to frame supportive attempts in a positive light. When a PWP may perceive support as threatening to the identity or relationship

(e.g., because he or she feels like a burden), using positive nonverbal cues can counteract that threat. If, for example, the partner maintains a patient, loving tone of voice while providing tangible assistance, the PWP is less likely to feel like he or she is burdening the partner.

Lastly, the strategy of *taking the other's perspective* can be helpful because it may enable the PWP or partner to reframe challenges of support. Taking the other's perspective can reduce relational strain by encouraging an understanding of the issues the other is facing. Results indicate that this strategy is likely to be useful when one person loses patience with the other, or when members of the couple have different preferences for communicating support (e.g., when one wants to talk about PD and the other does not). Attempting to understand the other's motivations and feelings may lead a PWP or partner to be more open to an alternative way of coping.

In conclusion, these eight strategies were reported by participants as effective in managing the costs and complications of support. In line with Goldsmith's (2004) normative/rhetorical approach, I have proposed *why* and *when* these particular strategies are likely to be effective. An examination of reasons why these strategies tend to be perceived as helpful elucidates the fact that they represent ways of balancing goals (e.g., the task goal of providing support with the identity goal of not threatening the person's sense of independence). To explain further, providing tangible support to a PWP can be identity-threatening because it may be perceived by the PWP as casting him or her as helpless. A strategy like *framing partners as equals* can be a sophisticated way of overcoming this challenge (i.e., by providing support while also reaffirming relational equity and acknowledging positive aspects of the PWP's identity). By illuminating the circumstances under which certain strategies are likely to be perceived as

effective in managing complications and costs of support, the current research is well-positioned to provide insight about practical implications, which are presented in the following section.

Practical Implications

Results of this study yield a variety of practical implications. In this section, implications for PWPs and their partners are first discussed. Then, implications for the PWP/partner relationship and the exchange of social support are considered.

Findings from this project demonstrate that, in addition to the physical symptoms of PD, PWPs typically encounter a tremendous amount of stress as a result of psychosocial challenges. Furthermore, most PWPs in the sample reported feeling ill-prepared to handle these psychosocial issues, indicating a need for accessible, well-informed interventions and a more complete model of health care for this population. Interventions might take several forms, such as one-on-one counseling sessions with a mental health provider specializing in PD-related issues; a group format that includes other PWPs; or a group format that includes not only other PWPs but also loved ones. Ideally, interventions that include other PWPs would be limited to people at roughly the same illness stage. The rationale for grouping people based on illness stage is two-fold: First, it increases the likelihood that people will be able to relate to the issues others are experiencing (e.g., newly diagnosed PWPs are likely to benefit from an education about basic facts related to the disease, whereas individuals who have had PD for a number of years may be more interested in learning about new treatment options on the horizon). Second, many participants said that they find it frightening or depressing to interact with PWPs who have a significantly more advanced case of the illness than they do (because they view it as an indication of what is to come in their own future); therefore, grouping interventions by PWPs' stage of illness may be an important factor in ensuring that PWPs do not discontinue participation.

Intervention topics for PWPs might include discussing psychosocial issues that are common to this context and providing recommendations for responding to these challenges. Just being aware that uncertainty, for example, is a nearly universal experience for PWPs may help reassure newly diagnosed patients that the overwhelming number of questions they have is normal. Also, discussing possible responses to uncertainty can alert PWPs to the adaptive response of trying to accept chronic uncertainty as a way of life (see also Brashers, 2001; Mishel 1990). For some PWPs, accepting uncertainty as a way of life may involve coming to terms with the fact that there are going to be “good days” and “bad days,” and that it is difficult to predict when those “bad days” will come. Furthermore, based on findings from the current project, intervention materials might advise PWPs to accept that it is okay to have days in which they are not productive, due to a sudden, unexpected increase in PD-related symptoms. In addition to uncertainty, interventions for PWPs should attend to identity issues including the occurrence of communication-debilitating symptoms. If PWPs know in advance how identity-threatening the disease can be, they may be better equipped to respond to identity challenges in adaptive ways. To that end, interventions might suggest preemptive ways of combating identity loss (e.g., consciously working to maintain a social life or acquiring new, valued hobbies that can be maintained even when the disease leads to further deterioration).

Health care practitioners should aim to cover some of these same issues in their interactions with PWPs—or at least be able to direct PWPs to resources regarding psychosocial challenges and how to cope. Participants in the current study indicated that their doctors rarely speak to them about psychosocial issues, instead focusing on the biomedical implications of the disease. Yet the stress caused by psychosocial effects can in fact impact the biomedical aspects (and vice versa), suggesting that a biopsychosocial model of care (in which a doctor attends to a

patient's physical, psychological, and social needs) would be ideal. In addition, because many PWP's said that their partner serves an important role during medical appointments (e.g., by listening, gathering, and providing information), health professionals should be willing to communicate with both members of the couple at the PWP's appointments.

The current project also has practical implications for partners. This research demonstrates that being the partner of a PWP involves a number of significant psychosocial challenges related to both caregiving and non-caregiving issues. Some PWP's in the current study even said that they feel their partner experiences more stress related to PD than they do. Nonetheless, partners are less likely to receive support than patients (Corbin & Strauss, 1988), making partners an important target group for interventions. Interventions for partners might discuss similar topics to those mentioned for PWP's. That is, partners can be made aware, at the outset, of some of the issues that they may encounter, both in relation to caregiving (e.g., shouldering increased responsibility) and non-caregiving (e.g., the pain of not being able to "rescue" the PWP from PD). Ways of managing these challenges should be discussed during partner interventions, including recommendations such as finding a way to maintain some aspect of pre-PD life by having an outlet (e.g., playing sports or getting together with friends). If partners are housebound because of a need to watch their PWP, they should also be advised to reach out to members of the couple's social network to ask for help (e.g., to have another family member stay with the PWP one morning per week to allow the partner to run errands).

Finally, practical implications regarding the PWP/partner relationship and the exchange of social support also emerged. A simple yet powerful implication relating to the couple's relational dynamic is that the language for educational materials should be chosen with care, and doctors need to be sensitive to labels as well. One PWP, Lisa, reported being distraught after her

doctor gave her husband an educational film to watch about “being a caregiver.” Lisa, who was recently diagnosed with the disease, was distressed by the identity and relational meanings implied by having her husband as a caregiver. This study also has implications for the exchange of social support. Although “there are no one-size-fits-all behaviors that are uniformly supportive across contexts” (Goldsmith, 2004, p. 162), findings do offer insight into which strategies are likely to be helpful under different circumstances. (See Table 4.) In an intervention geared toward couples, the dyad could even be given a list of strategies and provided the opportunity to role-play scenarios and discuss individual preferences for support (e.g., preferring to not receive support unless asking for it versus preferring to receive unsolicited support).

Limitations and Directions for Future Research

This study offers the significant contributions of (a) augmenting our understanding of psychosocial challenges and relational issues experienced by PWP and partners and (b) providing in-depth insight into how couples cope with these challenges via social support. The current project also has limitations that should be acknowledged. These limitations, and the directions for future research that they indicate, are discussed below.

First, one factor to consider is that data represent participants’ *perceptions*. Although gathering in-depth data relating to PWP and partners’ perspectives of the PD experience was precisely the intent of the project (and, in general, a strength rather than a limitation), relying on a person’s perception could be considered a weakness in terms of labeling support strategies as effective or ineffective. That is, members of a couple did not always report the same management strategies in their individual interviews; thus, it is difficult to know if, for instance, a partner’s perception of using humor to effectively manage challenges of support is congruent with the PWP’s perception of that strategy’s effectiveness.

In addition, the study relies on a nonprobability sample of PWPs and partners. It is possible that the couples who volunteered to participate may be different than non-participating couples in several ways. First, although PWPs in this sample varied widely in PD stage, it is logical to assume that PWPs who are at the most advanced stage of the disease are not proportionately represented (because they tend to not be well enough to participate). Similarly, this sample did not capture the couples at the worst end of the spectrum in terms of how their relationship was affected by PD because those couples may have separated or divorced (and currently being together was a participation criterion). An alternative option for a future study would be to recruit *former* couples to see how their relationship was affected by the disease and what role, if any, PD played in its dissolution. Finally, it may be that couples in this study experienced more challenges related to PD than other couples coping with this disease. (That is, perhaps people were motivated to volunteer for a study about PD because their lives have been dramatically impacted by this disease.) In sum, because this is not a random sample of the total population of PWPs and partners, caution must be exercised in generalizing the results to all couples coping with PD; nonetheless, it seems probable that the experiences of the 44 individuals in the study represent many of the issues of the larger population of PWPs and partners.

Another consideration is that interview data are limited to what people are willing to disclose. Thus, although in-depth interviews led to rich data in this project, interviews (and other self-report methods) can be constrained by factors such as a participant's desire to provide socially desirable responses. Some PWPs, for example, may have felt uncomfortable disclosing negative information about their partner for fear of seeming disloyal to him or her, or ungrateful for the care that he or she has provided. Conducting the interviews separately and ensuring

confidentiality, though, likely helped overcome these barriers—and, overall, participants did not seem to hold back at all during the interviews.

Finally, the relatively small sample size did not permit extensive analysis of the role of potential mitigating factors—such as age, gender, relational history, ethnicity, or illness stage—on the experience of psychosocial issues and the communication of social support. Preliminary findings suggest, however, that age plays a major role in adjustment to PD and the communication of support. Kelly, the partner of a PWP who was diagnosed in his thirties, explained:

No handyman, project-loving guy wants to hear, “Um, honey? Maybe you shouldn’t be using the ladder anymore.” This would be hard enough to tell [my husband] if he was 60.

Now consider that he first heard this from me in his 30’s.

It seems that the younger a PWP is, the more threatening PD is to his or her identity; older couples may experience fewer dilemmas of support because chronic illness is considered more “on time” when it occurs later in life. Future research would benefit from a more explicit examination of such factors.

Conclusion

This project demonstrates the dramatic psychosocial challenges and relational issues that PWP and partners can experience as a result of PD. Previous research in this area was relatively scarce (Brod et al., 1998). The current study extends past research by delineating a number of specific challenges affecting the PWP, partner, and their relationship. In addition, this project provides insight into the communication of social support within couples with PD (another area in which research was lacking; Schreurs et al., 2000) by examining support from a normative/rhetorical perspective (Goldsmith, 2004). Results offer several global conclusions

about PD (e.g., it is a highly-identity threatening and uncertainty-inducing illness), as well as specific details about *why* and *when* certain strategies are likely to be effective in managing challenges of support. The findings have important practical implications for PWPs and partners in terms of interventions and medical care.

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FOOTNOTES

¹ In 2004, Goldsmith referred to her approach to the study of social support as *rhetorical*. In earlier explanations of this perspective, she called it a *normative* framework (e.g., see Goldsmith & Fitch, 1997). For clarity, I have opted to use a joint phrasing of the terms (i.e., *normative/rhetorical*) throughout.

² Another line of research in which the term *dilemmas* is sometimes used is the body of work on relational dialectics (e.g., Baxter & Montgomery, 1996). In theories of relational dialectics, dilemmas (i.e., dialectics) are defined as ever-present contradictory forces (e.g., simultaneous desires for openness and privacy) that constantly pull individuals in different directions. In contrast, the dilemmas of support examined in Goldsmith's (2004) normative/rhetorical approach are situationally specific social challenges that emerge as a result of pursuing multiple goals in a communicative interaction. That is, during some support attempts, task, identity, and/or relational goals conflict (e.g., the task of giving particularly face-threatening advice may collide with the goal of protecting the other person's feelings), and dilemmas of support arise.

³ As discussed later in this chapter, the sometimes dyadic nature of coping and support is, however, addressed in the coping and social support literatures (e.g., see Bodenmann, 2005; Goldsmith, 2004).

⁴ Buffering models of support are not limited to any single approach: Regardless of whether social support is conceptualized as part of a social network, psychological, or communicative/interactional approach, the buffering hypothesis (Cohen & Wills, 1985) maintains that support serves a protective function during times of stress.

TABLES AND FIGURE

Table 1

Social Support Within Couples Coping with PD: Ways of Communicating Support

Assisting with activities of daily living

Examples: organizing PD medications; doing household chores; driving; helping with personal care tasks (e.g., dressing or going to the bathroom)

Helping the PWP stay active through joint activities

Examples: completing puzzles or playing games, exercising, shopping

Providing emotional support

Examples: providing comfort upon diagnosis (e.g., about medical care or relational commitment); listening to allow for other's cathartic release of emotions; helping person calm down when facing negative emotions related to PD

Providing informational support

Examples: sharing information from media sources; giving advice; accompanying PWP to medical appointments to help provide, listen to, interpret, and remember information

Encouraging perspective shifts

Examples: telling the PWP "it's okay" to need a nap; reframing identity challenges (e.g., using a cane)

Table 2

Social Support Within Couples Coping with PD: Costs and Complications of Support

Partners' differing approaches to coping can make support difficult

Examples: PWPs and partners having differing attitudes; varying desires for, or interpretations of, information; and incongruous preferences for talking about the disease

Support can be threatening to the PWP's identity as independent/capable

Example: partner offering to drive may imply to PWP that partner thinks he/she is incapable

Support can be interpreted as controlling

Examples: partner "putting words into [PWP's] mouth" at medical appointments; partner making meals and getting upset if PWP does not eat "enough"

Support can place unwanted emphasis on the disease

Example: talking about PD can be unpleasant or identity-threatening to PWP

Support can bring concerns about burdening the other

Examples: PWP feeling guilty about accepting partner's support when partner also has health problems, partner not wanting to burden PWP with his/her own PD-related worries

Support can lead to dependency

Examples: PWP becoming either *unable* or *unmotivated* to complete tasks on his/her own due to continuous help

Support can be draining

Example: partner feeling overwhelmed by providing support because of a sense that "it's all on me now"

Table 3

Social Support Within Couples Coping with PD: Strategies for Effectively Managing Complications and Costs of Support

Framing partners as equals

Example: partner saying, “You know, sweetheart, you’ve been so busy; you’ve been doing so much in the yard lately. Would you mind if I just did the checkbook this month?”

Relinquishing control

Examples: PWP “letting go” of activities (e.g., driving) and accepting help; partner giving PWP freedom to “come up with his own plan” of PD management

Having the partner follow the PWP’s lead

Examples: not providing tangible support unless the PWP asks for it, not talking about PD unless the PWP brings it up

Using humor

Examples: teasing, joking

Seeking/providing support indirectly or subtly

Example: PWP saying, “I think I need a stool softener” (instead of directly requesting that partner give him an enema to help with constipation from PD medications)

Having an outlet

Examples: partner golfing or attending “girls’ night out”

Using nonverbal cues

Example: partner maintaining a patient tone of voice while providing tangible support

Taking the other’s perspective

Example: partner reminding herself that “this is hard for [PWP], too” when becoming irritated at being asked for help

Table 4

Social Support Within Couples Coping with PD: Why and When Strategies are Likely to be Considered Effective in Managing Costs and Complications of Support

Framing partners as equals

Why helpful:

- minimizes threat to the PWP's identity because the PWP is altercast as equal when the partner offers/provides support
- minimizes threat to the relationship because the partner communicates in a manner that emphasizes interdependence and relational equity (i.e., reiterates couple's relational identity as equal partners)

Example of when most likely to be helpful:

- when PD necessitates tangible support because the PWP can no longer fulfill previous roles

Relinquishing control

Why helpful:

- can reduce relational strain that may occur when one or both partners perceive a power struggle
- by giving up control, the support provider is freed from being labeled as a "nag" and the support recipient is empowered by being altercast as independent and capable (e.g., capable of making decisions independently)

Example of when most likely to be helpful:

- when the partner has repeatedly offered help and the PWP does not want it (e.g., when the partner communicates advice and the PWP opts not to follow it)

Having the partner follow the PWP's lead

Why helpful:

- alleviates possibility of the partner offering/providing unwanted help that may be identity-threatening (or engaging in communication about PD when the PWP does not want to)

Examples of when most likely to be helpful:

- when independence is highly important to the PWP (such that offers to help with routine tasks would likely constitute a significant identity threat; e.g., in middle-aged PWPs with early-onset PD)
- when the PWP prefers not to talk about the illness because he or she considers communication about PD an unwanted reminder of the disease
- when the PWP is motivated and capable in terms of completing some tasks on his or her own (i.e., may not be the most effective strategy in very advanced cases of PD)
- when the partner knows that the PWP will in fact ask for help when it is needed (or bring up the topic of PD when he/she wants to talk about it)

Table 4 (cont.)

Using humor

Why helpful:

- if consistent with relational identity, communicating about PD in a light-hearted manner may help a couple to feel more comfortable and reduce any threat to their relational identity
- advice given in a joking manner may be less likely to make the PWP feel intruded upon (i.e., be less identity-threatening) because it can be “brushed off” as a joke

Example of when most likely to be helpful:

- when the relationship dictates it (i.e., when consistent with couple’s preferred style of communication)

Seeking/providing support indirectly or subtly

Why helpful:

- being indirect or subtle can make asking for or receiving support less face-threatening

Examples of when most likely to be helpful:

- when the nature of the support is particularly sensitive or identity-threatening (e.g., asking for an enema)
- when self-presentation is a concern (especially when in public)

Having an outlet

Why helpful:

- can help dissipate stress the partner feels related to PD (e.g., by providing an opportunity for distraction, enjoyment, or cathartic release of emotions)
- participating in own activities can help the partner maintain aspects of his or her pre-PD (and pre-caregiver) identity

Examples of when most likely to be helpful:

- when the partner has shouldered additional responsibility as a result of PD
- when the partner’s identity has been threatened by PD (e.g., as a result of becoming entrenched in caregiving tasks, or due to giving up social activity)

Using nonverbal cues

Why helpful:

- allows partners to frame support in a positive light

Example of when most likely to be helpful:

- when the PWP may perceive support as threatening to the identity or relationship (e.g., because he or she feels like a burden), positive nonverbals can counteract that threat

Taking the other’s perspective

Why helpful:

- can enable the PWP or partner to reframe challenges of support

Table 4 (cont.)

- can reduce relational strain by encouraging an understanding of the challenges the other is facing

Examples of when most likely to be helpful:

- when one person loses patience with the other
 - when members of the couple have different preferences for communicating support
-

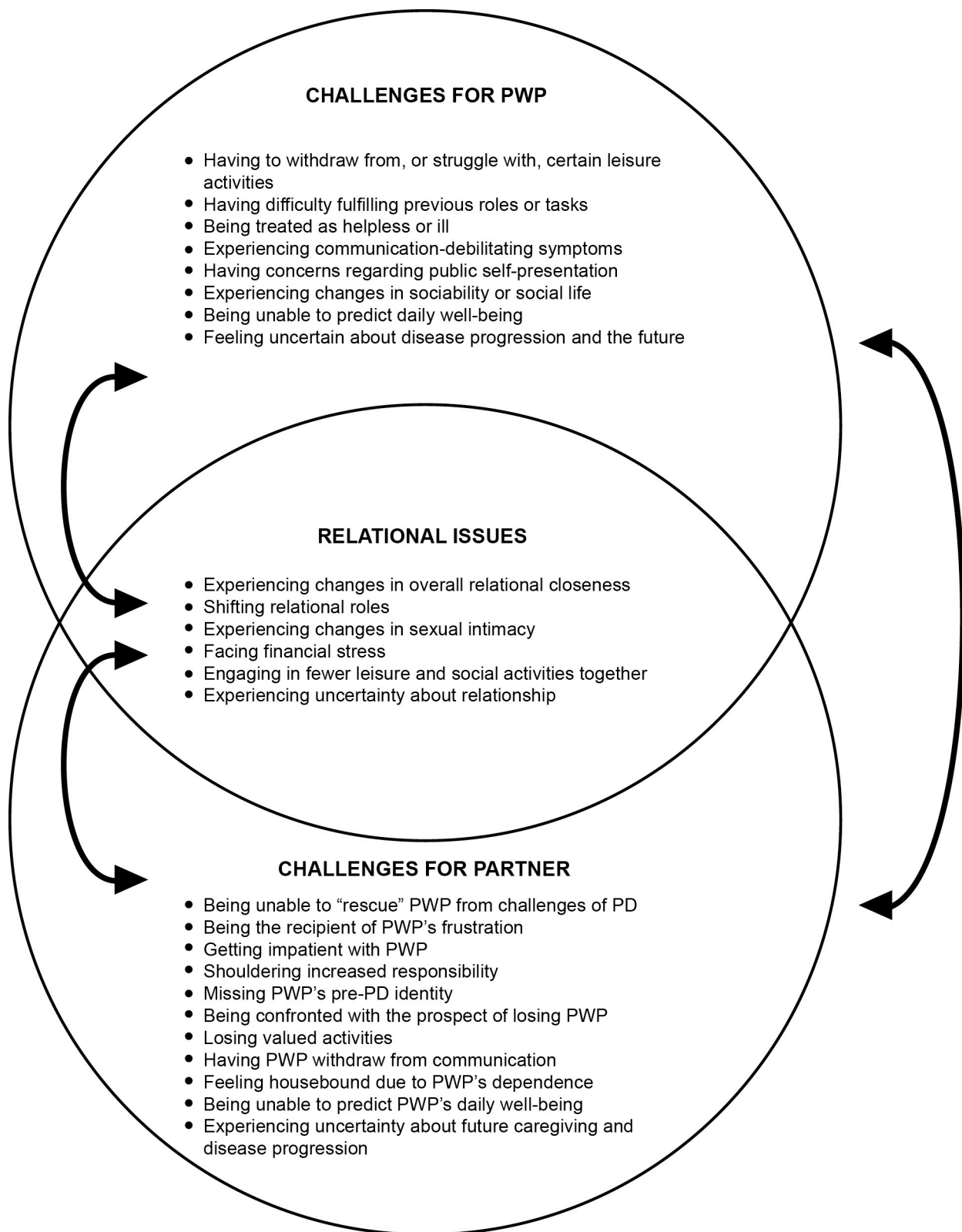


Figure 1. Psychosocial challenges and relational issues experienced by people with Parkinson’s disease (PWP) and their partners. Arrows represent the fact that PWP challenges, partner challenges, and relational issues all influence one another.

APPENDIX A:

Patient Demographic Questionnaire

Thank you for participating in this study. Filling out this brief questionnaire will help in the recording of demographic information.

1. What is your gender? Male _____ Female _____
2. What is your age? _____
3. What is your racial/ethnic identity? _____
4. What is your current relationship status? (Examples: married, cohabitating romantic partners)

5. How long have you been with your current spouse/partner? _____
6. Do you have any children? If so, please list their ages: _____
7. Please circle the highest level of education you have completed.

Some high school	Some college	Graduate degree completed
High school	College graduate	Post-doctoral
8. What is your employment status? (Examples: employed, unemployed, retired)

9. How long ago were you diagnosed with Parkinson's disease? _____
10. Please indicate, by checking a line below, which of the following categories best describes your stage of Parkinson's disease:

____ No visible symptoms of Parkinson's disease
____ Symptoms on only *one* side of the body
____ Symptoms on *both* sides of the body and *no* difficulty walking
____ Symptoms on *both* sides of the body and *minimal* difficulty walking
____ Symptoms on *both* sides of the body and *moderate* difficulty walking
____ Symptoms on *both* sides of the body and *unable* to walk

11. Besides Parkinson's disease, have you been diagnosed with any other chronic illness(es)? If so, please list the illness(es) and how long ago you were diagnosed:

12. Has your spouse/partner been diagnosed with any chronic illness(es)? If so, please list the illness(es) and how long ago he/she was diagnosed:

APPENDIX B:

Partner Demographic Questionnaire

Thank you for participating in this study. Filling out this brief questionnaire will help in the recording of demographic information.

1. What is your gender? Male _____ Female _____
2. What is your age? _____
3. What is your racial/ethnic identity? _____
4. What is your current relationship status? (Examples: married, cohabitating romantic partners)

5. How long have you been with your current spouse/partner? _____
6. Do you have any children? If so, please list their ages: _____
7. Please circle the highest level of education you have completed.

Some high school	Some college	Graduate degree completed
High school	College graduate	Post-doctoral
8. What is your employment status? (Examples: employed, unemployed, retired)

9. How long ago was your spouse/partner diagnosed with Parkinson's? _____
10. Please indicate, by checking a line below, which of the following categories best describes your spouse's/partner's stage of Parkinson's disease:

____ No visible symptoms of Parkinson's disease
____ Symptoms on only *one* side of the body
____ Symptoms on *both* sides of the body and *no* difficulty walking
____ Symptoms on *both* sides of the body and *minimal* difficulty walking
____ Symptoms on *both* sides of the body and *moderate* difficulty walking
____ Symptoms on *both* sides of the body and *unable* to walk

11. Besides Parkinson's disease, has your spouse/partner been diagnosed with any other chronic illness(es)? If so, please list the illness(es) and how long ago he/she was diagnosed:

12. Have you been diagnosed with any chronic illness(es)? If so, please list the illness(es) and how long ago you were diagnosed:

APPENDIX C: Patient Interview Schedule

Thank you very much for your participation. As you know, the purpose of this study is to collect information about couples coping with PD that will help other patients and their loved ones. I'm going to ask you a series of questions about your experiences with this disease, including the ways in which it has affected you and your partner. There are no right or wrong answers; I'm simply interested in learning about your experiences. If there are any questions that you'd prefer not to answer, or if you have any questions for me at any point along the way, please let me know. Do you have any questions before we get started?

Pre-Diagnosis Experiences

1. To begin, please tell me a little about when you first started experiencing symptoms of PD (before you were diagnosed).

-How long did it take from the time you started experiencing symptoms until diagnosis?

-What was that period (during which symptoms were unexplained) like for you? How about for your partner?

Diagnosis Experiences

2. Next, please tell me about the experience of being diagnosed with PD.

-How long ago were you diagnosed?

-What was your reaction when you received the diagnosis of PD? What was your partner's reaction to it?

-How did you feel about sharing this diagnosis with others? Whom did you tell?

-Were you uncertain (i.e., did you have any questions or things you felt unsure of) about anything related to the disease when you were first diagnosed? If yes, probe: What types of things were you uncertain about? What did you do about your uncertainty?

Changes in Patient (Self) Due to PD

3. Can you please tell me a little about what your life has been like in the time since you received the diagnosis? In what ways has your life changed as a result of the disease?

-Has PD affected your overall quality of life? If yes, probe: What are these changes like? What do you find is the best way to manage these changes, and why?

-Has it changed your daily routines? If yes, probe: What are these changes like? What do you find is the best way to manage these changes, and why?

-Sometimes a chronic illness like PD can affect how you think or feel. Has the disease affected you emotionally (e.g., caused depression or mood changes, changed the way you view yourself or your future)? If yes, probe: What are these changes like? What do you find is the best way to manage these changes, and why?

-I asked a bit earlier if you initially had any uncertainty (questions or things you felt unsure about) as a result of being diagnosed. How about now: Do you experience any uncertainty at this point in the progression of your disease? If yes, probe: About what? How do you manage this uncertainty?

-Some people with PD mention that it has affected their ability to communicate or interact with others. Is that something you've experienced? If yes, probe: What are these changes like? What do you find is the best way to manage these changes, and why?

Relational Changes Due to PD

4. I'd like to ask now about how your relationships have been affected by PD.

-Have some aspects of your relationship with your partner changed as a result of the disease? If yes, please describe these changes. Probes:

-Has it changed the activities you do together? If yes, please describe.

-Has it changed the way you divide household chores? If yes, please describe.

-Has it changed the way that you and your partner talk to one another? If yes, please describe.

-What do you find is the best way to manage these changes, and why?

-Have your other relationships (e.g., with other family members, friends) changed as a result of PD? If yes, please describe these changes.

-What do you find is the best way to manage these changes, and why?

Perceived Changes in Partner Due to PD

5. Besides what we've discussed so far, have you noticed any changes in your partner as a result of the disease? If yes, probe: What types of changes have you noticed?

Communication About PD

6. Do you talk to your partner about PD? If yes, probe:

-What topics do you discuss? Probe: Can you give me an example of a recent conversation you and your partner had related to PD?

-Does talking with your partner make it easier or harder to deal with PD? Why?

-Can you give me an example of a particularly good conversation about PD? Why was it good?

-How about a particularly bad conversation? Why was it bad?

7. Is there anything related to the disease that you would rather not talk about with your partner? If yes, please describe. Probe: Why would you rather not talk about these topics with your partner?

8. Is there anything related to the disease that you think your partner would rather not talk about with you? If yes, please describe. Probe: Why do you think your partner would rather not talk about these topics with you?

Social Support (General)

9. Have people in your life (e.g., partner, other family members, friends, coworkers) done anything that has helped you deal with having PD? If yes, probe:

-Who has helped? In what ways? Why was it helpful?

-Are there any challenges associated with this help?

10. Has anyone done anything that has not been helpful? If so, what? Probe: Why was it unhelpful?

11. Have you been to a support group for individuals with PD? Probe:

-If so, what was this experience like?

-What do you think the advantages or disadvantages of talking to peers (others affected by the disease) are (or would be)?

Social Support (Specific)

12. Many people report that some of the changes of PD can be quite stressful. Probe: Can you think of a *specific* example of a challenge you've recently faced (i.e., something stressful that has occurred as a result of the disease)?

-In what ways did you try to cope with this/these stressor(s)? Which ways were more/less helpful? Why?

-What role, if any, does your partner play in the way you cope (in this specific example and in general)? If applicable: Is this helpful/unhelpful? Why?

13. What do you think are the most stressful things related to PD for your partner? Probe: Can you think of a *specific* example of a challenge he/she has recently faced?

-How did he/she respond?

-What role, if any, do you try to play in the way your partner copes (in this specific example and in general)? If applicable: Is this helpful/unhelpful? Why?

14. What do you think are some of the most stressful things related to PD for your relationship? (Probe: Can you think of a *specific* example of a relationship challenge you and your partner have recently faced?)

-How did you respond? How did your partner respond?

-Is there anything that you and your partner do together that helps you cope with this/these stressor(s)? If applicable: Is this helpful/unhelpful? Why?

Closing

15. What advice you would give to someone who was recently diagnosed with PD? And to his or her loved ones?

16. Is there anything that I didn't ask you about that you would like to add?

Thank you so much again for your participation.

APPENDIX D: Partner Interview Schedule

Thank you very much for your participation. As you know, the purpose of this study is to collect information about patients and partner coping with PD that will help other couples affected by this disease. I'm going to ask you a series of questions about your experiences with this disease, including the ways in which it has affected you and your partner. There are no right or wrong answers; I'm simply interested in learning about your experiences. If there are any questions that you'd prefer not to answer, or if you have any questions for me at any point along the way, please let me know. Do you have any questions before we get started?

Pre-Diagnosis Experiences

1. To begin, please tell me a little about when your partner first started experiencing symptoms of PD (before he/she was diagnosed).

-How long did it take from the time he/she started experiencing symptoms until diagnosis?

-What was that period (during which symptoms were unexplained) like for you? How about for your partner?

Diagnosis Experiences

2. Next, please tell me about the experience of your partner being diagnosed with PD.

-How long ago was he/she diagnosed?

-What was your reaction when you heard your partner's diagnosis of PD? What was his/her reaction to it?

-Did you share this diagnosis with others? Whom did you tell?

-Were you uncertain (i.e., did you have any questions or things you felt unsure of) about anything related to the disease when your partner was first diagnosed? If yes, probe: What types of things were you uncertain about? What did you do about your uncertainty?

Perceived Changes in Patient Due to PD

3. Can you please tell me a little about your perceptions of what your partner's life has been like in the time since he/she was diagnosed? In what ways has his/her life changed as a result of the disease?

-Has PD affected his/her overall quality of life? If yes, probe: What are these changes like?

-Has it changed his/her daily routines? If yes, probe: What are these changes like?

-Sometimes a chronic illness like PD can affect how a patient thinks or feels. Has PD affected your partner emotionally (e.g., caused depression or mood changes, changed the way he/she views him/herself or the future)? If yes, probe: What are these changes like?

-Do you think PD has affected your partner's ability to communicate or interact with others? If yes, probe: What are these changes like?

Relational Changes Due to PD

4. I'd like to ask now about how your relationships have been affected by the fact that your partner has PD.

-Have some aspects of your relationship with your partner changed as a result of the disease? If yes, please describe these changes. Probes:

-Has it changed the activities you do together? If yes, please describe.

-Has it changed the way you divide household chores? If yes, please describe.

-Has it changed the way that you and your partner talk to one another? If yes, please describe.

-What do you find is the best way to manage these changes, and why?

-Have your other relationships (e.g., with other family members, friends) changed as a result of your partner's PD? If yes, please describe these changes.

-What do you find is the best way to manage these changes, and why?

Changes in Partner (Self) Due to PD

5. In what ways has your life changed as a result of your partner's disease? Probe:

-What types of changes have you noticed (e.g., emotional, physical)?

-Do you consider yourself to be your partner's primary caregiver? If yes, please describe what types of tasks that entails.

-I asked a bit earlier if you initially had any uncertainty (questions or things you felt unsure about) as a result of your partner being diagnosed. How about now? Do you experience any uncertainty at this point in the progression of your partner's disease? If yes, probe: About what? How do you manage this uncertainty?

Communication About PD

6. Do you talk to your partner about PD? If yes, probe:

-What topics do you discuss? Probe: Can you give me an example of a recent conversation you and your partner had related to PD?

-Does talking with your partner make it easier or harder for you to deal with your partner's PD? Why?

-Can you give me an example of a particularly good conversation about PD? Why was it good?

-How about a particularly bad conversation? Why was it bad?

7. Is there anything related to the disease that you would rather not talk about with your partner? If yes, please describe. Probe: Why would you rather not talk about these topics with your partner?

8. Is there anything related to the disease that you think your partner would rather not talk about with you? If yes, please describe. Probe: Why do you think your partner would rather not talk about these topics with you?

Social Support (General)

9. Have people in your life (e.g., partner, other family members, friends, coworkers) done anything that has helped you deal with having your partner having PD? If yes, probe:

-Who has helped? In what ways? Why was it helpful?

-Are there any challenges associated with this help?

10. Has anyone done anything that has not been helpful? If so, what? Probe: Why was it unhelpful?

11. Have you been to a support group for partners of individuals with PD? Probe:

-If so, what was this experience like?

-What do you think the advantages or disadvantages of talking to peers (other partners affected by the disease) are (or would be)?

Social Support (Specific)

12. Many people report that the experience of having a partner with an illness like PD can be stressful at times. Probe: Can you think of a *specific* example of a challenge you've recently faced (i.e., something stressful that has occurred as a result of the disease)?

-In what ways did you try to cope with this/these stressor(s)? Which ways were more/less helpful? Why?

-What role, if any, does your partner play in the way you cope (in this specific example and in general)? If applicable: Is this helpful/unhelpful? Why?

13. What do you think are the most stressful things related to PD for your partner? Probe: Can you think of a *specific* example of a challenge he/she has recently faced?

-How did he/she respond?

-What role, if any, do you try to play in the way your partner copes (in this specific example and in general)? If applicable: Is this helpful/unhelpful? Why?

14. What do you think are some of the most stressful things related to PD for your relationship? (Probe: Can you think of a *specific* example of a relationship challenge you and your partner have recently faced?)

-How did you respond? How did your partner respond?

-Is there anything that you and your partner do together that helps you cope with this/these stressor(s)? If applicable: Is this helpful/unhelpful? Why?

Closing

15. What advice you would give to someone whose partner (or other loved one) was recently diagnosed with PD? And to the patient?

16. Is there anything that I didn't ask you about that you would like to add?

Thank you so much again for your participation.